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# Patient Perspectives on the Impact of Living With Hidradenitis Suppurativa: Results From the Global ‘HS Uncovered’ Burden of Disease Survey

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## ABSTRACT

**Background:** Hidradenitis suppurativa (HS) is a chronic, painful inflammatory skin disease. There is a need to evaluate how patients experience their disease.

**Objectives:** The HS Uncovered survey was conducted to understand patient activation, the patient journey and burden of disease.

**Methods:** HS Uncovered was a real-world, quantitative, online survey completed by adults who self-reported a diagnosis/suspected diagnosis of HS. The survey included patient-reported outcome measures (PROMs) and non-PROM-related questions and was conducted between December 2022 to March 2023 in six countries (US, UK, Germany, France, Italy, Spain). PROMs included the Patient Activation Measure (PAM13; primary endpoint), Dermatology Life Quality Index (DLQI), Work Productivity and Activity Impairment (WPAI) and Hospital Anxiety and Depression Scale (HADS) tools (Spain excluded from PROM analyses).

**Results:** Overall, 656 participants were included ( $N = 505$ , diagnosed HS;  $N = 151$ , suspected HS). Of 425 diagnosed participants, 66% reported high (level 3/4) PAM13 scores. A very large (DLQI score 11–20) and extremely large (DLQI score 21–30) effect of HS on QoL was reported by 41% and 28% of participants, respectively. A very large to extremely large effect of HS on QoL (DLQI score 11–30) was reported by 67% and 73% of patients with level 3 and 4 PAM13 scores, respectively. Overall, 53% and 29% of diagnosed participants reported abnormal anxiety and depression, respectively. The percentage of work impairment due to HS in employed diagnosed participants ( $N = 302$ ) was 52%. Of diagnosed females, 52% considered HS a concern for family planning. Overall ( $N = 656$ ), 58% of participants considered pain relief the most important treatment feature.

**Conclusions:** Despite participants having high activation levels, HS had a negative impact on QoL, mental health, work and activity. There is an unmet need for effective treatments that provide sustained pain reduction and improve work productivity in HS.

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## Summary

- **Why was the study undertaken?**
  - To understand the impact and burden of hidradenitis suppurativa (HS) from the patient's perspective, to assess patients' level of knowledge, skills and confidence to make effective decisions about their condition and to understand the patient's journey through the healthcare system.
- **What does this study add?**
  - Over 60% of people living with HS had a high activation level, indicating they are taking action and trying to manage their own health. Despite this, HS had a negative impact on quality of life, mental health, and work productivity.
- **What are the implications of this study for disease understanding and/or clinical care?**
  - Improvements are needed in the patient journey to ensure people living with HS receive a timely diagnosis and access to healthcare professionals and effective disease and comorbidity management. There is an unmet need for effective treatments.

## 1 | Introduction

Hidradenitis suppurativa (HS) is a debilitating, inflammatory skin disease that has a substantial disease and comorbidity burden [1–4]. The reported prevalence of HS ranges from 0.05% to 4.10% [5–7]. Females are more frequently affected than males [8], and a higher prevalence has been reported in African American people than in White people [8–10].

HS lesions are associated with chronic and intense pain, pruritus, malodour, drainage, scarring, mood disorders and sexual dysfunction, which have a substantial impact on quality of life (QoL) and work productivity [2, 3, 11, 12]. People with HS reportedly experience increased pain, depression and a greater impact on QoL compared to people with other dermatological diseases [13–15]. These challenges are further augmented by average diagnostic delays of around 7 to 10 years [16, 17].

Patient activation, defined as understanding one's role in the care process and having the knowledge, skill and confidence to take on that role, is believed to have an impact on adherence to treatment regimens, health-seeking behaviour and participation in care decisions [18–20]. Better care outcomes are associated with higher patient activation measure (PAM) scores [20].

People with HS often need to adhere to complex treatment regimens; however, little is known about patient activation in HS. Further, there is a lack of large-scale patient level data in relation to the psychosocial and financial impact of HS, as well as the patient perspective on treatment modalities, and the effect on family planning and pregnancy.

To address these gaps, the HS Uncovered survey was conducted, which aimed to understand the patient perspective of various aspects of living with HS, including level of patient activation, the patient journey, disease burden, treatment and management.

## 2 | Methods

### 2.1 | Study Design

HS Uncovered was a real-world, quantitative, online survey completed by people living with HS. The survey comprised 70 questions and took approximately 35 min to complete. The survey included validated patient-reported outcome measures (PROMs) and non-PROM-related questions specific to the HS patient journey and HS treatment and management. The survey was conducted between December 2022 and March 2023 in six countries (France, Germany, Italy, Spain, United States, United Kingdom). The survey was developed in collaboration with HS experts comprising dermatologists, surgeons and patient representatives. The survey was conducted in accordance with applicable national laws and regulations.

### 2.2 | Primary Objective

The primary objective was to assess the level of activation in people with HS. This was assessed using the PAM-13 [21], which assesses an individual's knowledge, skills and confidence in managing their health. PAM responses were scored on a scale from 0 to 100, correlating to four levels of activation: level 1 ( $\leq 47.0$ ; disengaged and overwhelmed), level 2 (47.1–55.1; becoming aware but still struggling), level 3 (55.2–71.1; taking action and gaining control) and level 4 (71.2–100; maintaining behaviours and pushing further). A PAM-13 score  $\geq 55.2$  was considered activated.

### 2.3 | Secondary Objectives

Secondary objectives were to understand the patient journey through the healthcare system, determine the key contributors to delays in diagnosis and investigate the burden of disease and overall impact on QoL. The patient journey was assessed via questions focusing on symptom onset and presentation, diagnosis, management and treatment. The burden of disease and overall impact on QoL were evaluated using the Dermatology Life Quality Index (DLQI) [22], Hospital Anxiety and Depression Scale (HADS) [23] and Work Productivity and Activity Impairment (WPAI) Questionnaire [24]. Participants with no occupation completed the WPAI question on activity impairment only. Non-PROM related questions assessed the amount of money spent on HS per month, the effect of HS on pain/emotions/self-esteem/intimacy/social and personal life and potential concerns over family planning.

### 2.4 | Participants

Included participants were adults ( $\geq 18$  years) residing in a participating country who self-reported a diagnosis of HS or suspected HS, reported HS symptoms (nodules/boils, abscesses, tunnels), had  $\geq 2$  outbreaks in the last 6 months, had seen a doctor/physician about their skin disease, and had not participated in surveys related to HS in the last 4 weeks. All participants provided written informed consent to participate in the survey.

## 2.5 | Recruitment

Potential participants were identified through patient organisations and using a direct-to-patient strategy combining different approaches. The three main methodologies utilised to recruit participants into the trial were via patient panels, patient groups and dermatologists' referral. 'Patient panels' are large panels of people who have signed up to participate in surveys, noting any health conditions that they may have. In the current study, invites were sent to potential participants, who needed to pass a recruitment questionnaire to determine if they had HS. Patient groups distributed information on the study to their members. Potential participants were required to pass a screening questionnaire. Potential participants who were identified via dermatologist referrals were required to pass the screening questionnaire. Additional detail on the panels/groups used to recruit participants is provided in Supporting Information S1: Table S1.

## 2.6 | Data Analysis

Univariate descriptive analysis was conducted for key variables (e.g., sociodemographic characteristics). Summary statistics were calculated for continuous and categorical data. Bivariate analyses were performed to investigate the relationship between patient activation and patient characteristics. Linear regression analysis was used to evaluate the multivariate relationship between patient activation and selected characteristics, controlling for age, gender and ethnicity. Comparisons across subgroups were tested for significance at the 95% confidence interval.

Spain was shown non-licensed adaptations of the PROMs tools due to the survey classification of the research locally. Therefore, results for Spain are not included in the PROM analysis results (PAM-13, DLQI, HADS, WPAI).

Data were typically analysed according to both people with diagnosed HS or suspected HS; the current manuscript predominantly focuses on those with diagnosed HS. Additionally, analyses were conducted by gender (male, female) and by ethnicity (White, Black, Hispanic). The gender and ethnicity analyses included people with both diagnosed and suspected HS. Ethnicity was not asked in France or Germany due to compliance reasons.

## 3 | Results

### 3.1 | Participant Overview

Overall, 656 participants were included in this survey ( $N = 505$ , diagnosed HS;  $N = 151$ , suspected HS; Supporting Information S1: Figure S1); 23% were from the US, 16% were from Italy, and 15% each were from the UK, Spain, Germany and France, respectively. The mean (standard deviation [SD]) age was 41 (11) years and 65% were female. In total, 556 ( $N = 425$ , diagnosed;  $N = 131$  suspected) participants completed the PROMS;

**TABLE 1** | Participant demographics and disease characteristics.

|                                    | Total ( $N = 656$ ) |
|------------------------------------|---------------------|
| Age, years, mean (SD)              | 41 (11)             |
| Age group, years, $n$ (%)          |                     |
| 19–25                              | 47 (7%)             |
| 26–35                              | 176 (27%)           |
| 36–45                              | 239 (36%)           |
| 46–55                              | 121 (18%)           |
| 56–65                              | 49 (7%)             |
| 66–80                              | 24 (4%)             |
| Gender, female, $n$ (%)            | 428 (65%)           |
| Diagnosed HS                       | 345 (81%)           |
|                                    | $N = 428$           |
| Suspected HS                       | 83 (19%)            |
|                                    | $N = 428$           |
| Gender, male, $n$ (%)              | 228 (35%)           |
| Diagnosed HS                       | 160 (70%)           |
|                                    | $N = 228$           |
| Suspected HS                       | 68 (30%)            |
|                                    | $N = 228$           |
| Ethnicity, $n$ (%)                 | $N = 456$           |
| White                              | 363 (80%)           |
| Black                              | 31 (7%)             |
| Asian                              | 7 (2%)              |
| Hispanic                           | 45 (10%)            |
| Other                              | 10 (1%)             |
| People with HS symptoms, $n$ (%)   |                     |
| Abscesses                          | 551 (84%)           |
| Nodules and boils                  | 492 (75%)           |
| Tunnels                            | 339 (52%)           |
| Most affected body parts, $n$ (%)  |                     |
| Groin                              | 436 (66%)           |
| Armpit                             | 429 (65%)           |
| Most common comorbidities, $n$ (%) |                     |
| Acne                               | 167 (25%)           |
| Eczema                             | 152 (23%)           |
| Arthritis                          | 124 (19%)           |
| Psoriasis                          | 122 (19%)           |

Abbreviations: HS, hidradenitis suppurativa;  $N$ , total number of participants;  $n$ , number of people in the group; SD standard deviation.

Spain not included in PAM-13, DLQI, HADS, and WPAI results (Supporting Information S1: Figure S1). Overall, 456 participants were included in the ethnicity analysis (France and Germany not included). The majority of participants (80%) were White, 10% were Hispanic and 7% were Black (Table 1). Details on HS symptoms, affected body area, and comorbidities, are included in Table 1.

## 3.2 | Burden of Disease

### 3.2.1 | Patient Activation (PAM-13) and QoL (DLQI)

In diagnosed participants ( $N = 425$ ), 66% reported high PAM activation levels (level 3–4) (Supporting Information S1: Figure S2). Overall ( $N = 556$ ), a significantly greater proportion of females (29%) reported a PAM level 4 vs. males (19%). No significant differences between males and females were observed for PAM levels 1–3 (Supporting Information S1: Figure S2). A significantly greater proportion of White participants (18%) reported a PAM level 1 vs. Black participants (3%). No significant differences were observed across other evaluated ethnic backgrounds (Supporting Information S1: Figure S2) or between countries (Supporting Information S1: Table S2).

A very large to extremely large effect of HS on QoL (DLQI score 11–30) was reported by 67% and 73% of diagnosed participants with level 3 and 4 PAM-13 scores, respectively (Figure 1).

In diagnosed participants ( $N = 425$ ), 41% reported that HS had a very large effect (DLQI score 11–20) on their QoL, while 28% reported that it had an extremely large effect (DLQI score 21–30). Overall ( $N = 556$ ), similar findings were observed for males and females (Figure 2). A significantly greater proportion of Hispanic participants (41%) reported an extremely large effect, compared to Black participants (13%). Significantly more diagnosed participants in the US (36%) reported that HS had an extremely large effect on their life over the past week compared to participants in the UK (21%) (Supporting Information S1: Table S2).

### 3.2.2 | Mental Health (HADS)

In diagnosed participants ( $N = 425$ ), 53% reported abnormal (HADS score 11–21) anxiety and 29% reported abnormal depression (Figure 3a,b). Overall ( $N = 556$ ), the proportion of participants with abnormal anxiety was broadly similar across

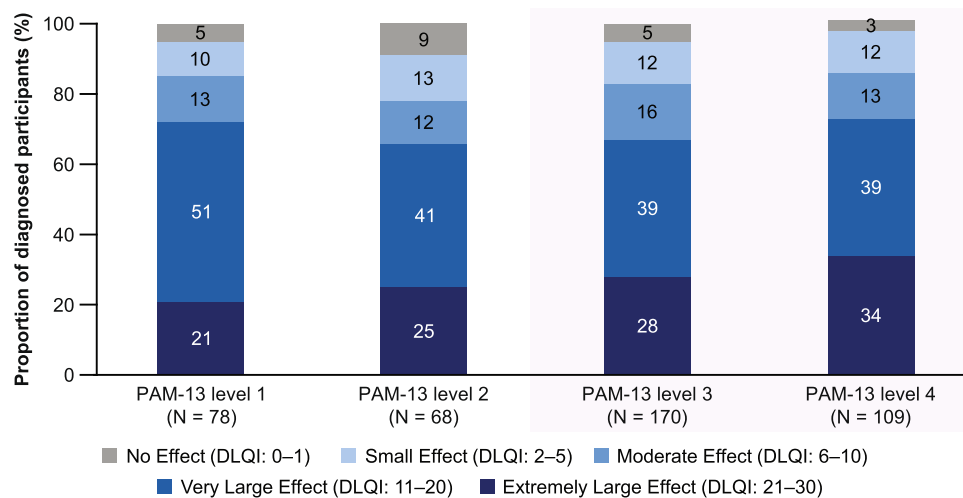


**FIGURE 1** | Reported quality of life impact of HS, by PAM-13 level, in diagnosed participants. DLQI, Dermatology life Quality Index; HS, hidradenitis suppurativa; N, number of participants; PAM, patient activation measure.

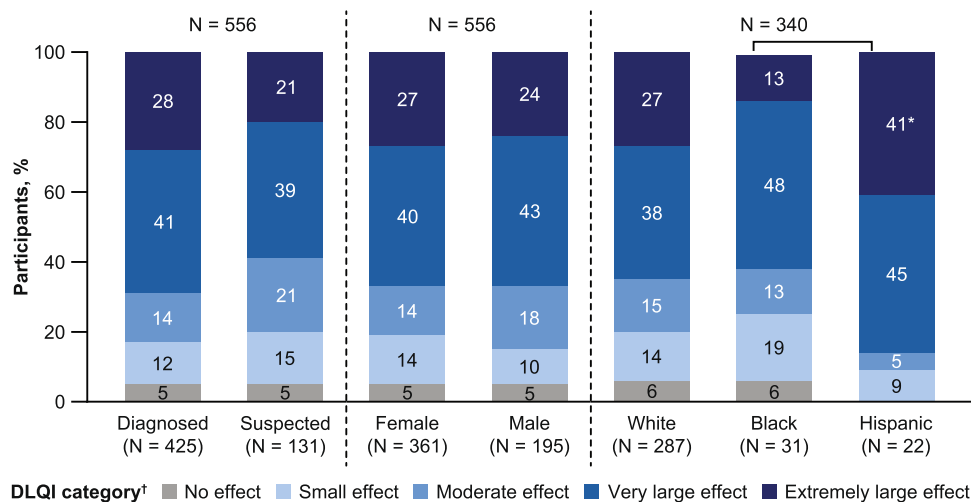


**FIGURE 2** | DLQI categories for participants with diagnosed and suspected HS, overall and stratified by gender and ethnicity. \*Significant difference (tested at 95% confidence); †DLQI scoring: 0–1, no effect; 2–5, small effect; 6–10, moderate effect; 11–20, very large effect; 21–30, extremely large effect. Spain not included in this analysis. The gender and ethnicity analyses included people with both diagnosed and suspected HS. Ethnicity was not asked in France or Germany due to compliance reasons. Percentages may not total 100 due to rounding. DLQI, Dermatology Life Quality Index; HS, hidradenitis suppurativa; N, number of participants.

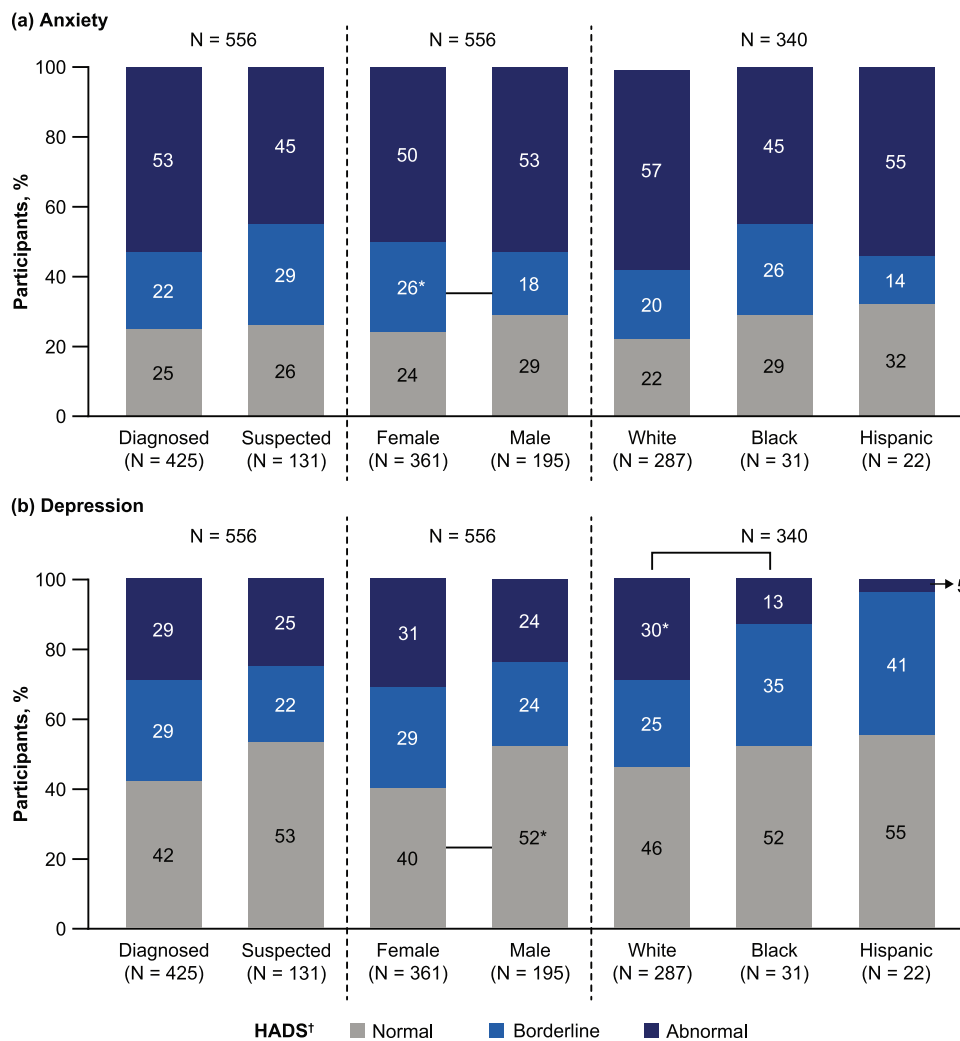


**FIGURE 3** | The proportion of participants with (a) anxiety and (b) depression, based on HADS score, for participants with diagnosed and suspected HS, overall and stratified by gender and ethnicity. \*Significant difference (tested at 95% confidence); <sup>†</sup>HADS scoring: 0–7, normal; 8–10, borderline abnormal; 11–21, abnormal. Note: Spain not included in this analysis. The gender and ethnicity analyses included people with both diagnosed and suspected HS. Ethnicity was not asked in France or Germany due to compliance reasons. Percentages may not total 100 due to rounding. HADS, Hospital Anxiety and Depression Scale; HS, hidradenitis suppurativa; N, number of participants.

males and females; however, a slightly higher proportion of females (31%) reported abnormal depression than males (24%). A smaller proportion of Black participants (45%) reported abnormal anxiety levels versus White (57%) and Hispanic participants (55%) (Figure 3a). A significantly greater proportion of White participants (30%) experienced abnormal depression than Black participants (13%) (Figure 3b).

A higher proportion of diagnosed participants in the US (67%), UK (56%) and France (54%) reported abnormal anxiety levels vs. Italy (48%) and Germany (38%). A higher proportion of participants in the UK (35%), France (34%), Germany (33%) and Italy (30%) reported abnormal depression levels vs. the US (17%) (Supporting Information S1: Table S2).

### 3.2.3 | Work Productivity and Activity Impairment

Overall (N = 302), 85% of participants reported some level of work productivity loss, while 55% reported absenteeism, 81%

reported presenteeism, and 86% reported activity impairment (Figure 4a). Fewer females (80%) than males (94%) reported work productivity loss. The proportion of work impairment was 52%, absenteeism was 19%, presenteeism was 44%, and activity impairment was 48% (Figure 4b). No substantial differences in work productivity loss were observed by ethnicity. Diagnosed participants (N = 302) reported a mean of 8 h missed from work over the past 7 days due to HS. Diagnosed participants in the US missed the most hours (12 h), while those in Germany missed the fewest (5 h) (Supporting Information S1: Table S2).

### 3.2.4 | Impact of HS on Finances and Family Planning

Diagnosed participants (N = 505) reported that the amount of money spent on HS in an average month ranged from €0 to €2778 (mean: €214). The mean monetary spend per month on HS was highest in the US (€591), followed by Italy (€233), France (€158), the UK (€154), Spain (€79) and Germany (€74) (per 2023 currency conversion).

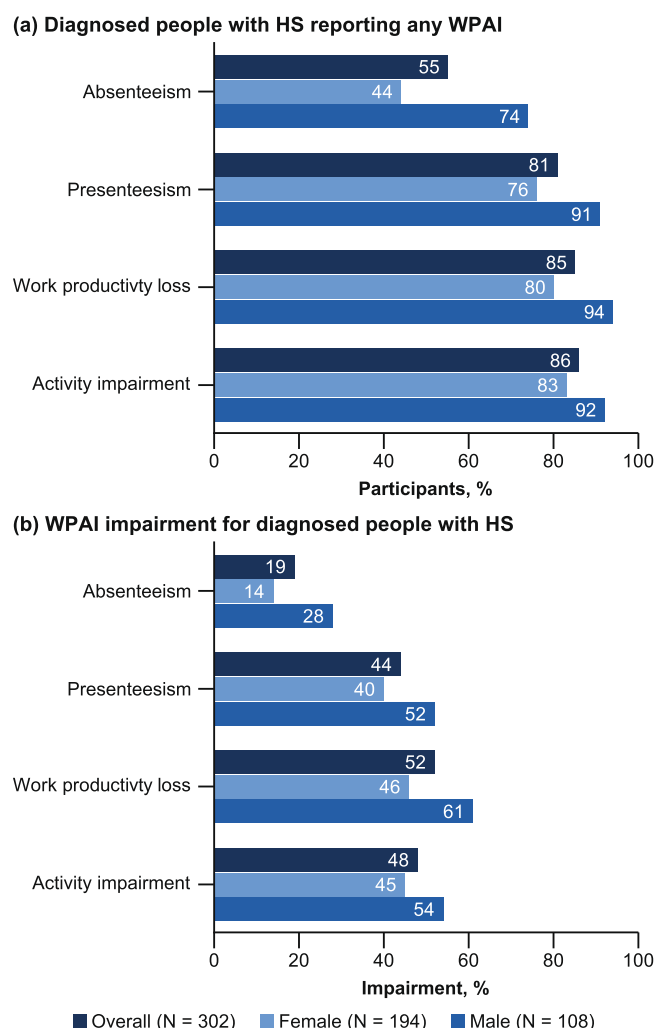


**FIGURE 4** | Impact on work productivity and activity in diagnosed participants with HS, in terms of (a) the proportion of participants reporting any WPAI and (b) proportion of impairment. Absenteeism, % of work time missed due to HS; presenteeism, % impairment while working due to HS; work productivity loss, % overall work impairment due to HS; activity impairment, % activity impairment due to HS. Note: Spain not included in this analysis. Participants with no occupation completed the question on activity impairment only. HS, hidradenitis suppurativa; N, number of participants; WPAI, Work Productivity and Activity Impairment. (a) Diagnosed people with HS reporting any WPAI. (b) WPAI impairment for diagnosed people with HS.

Among diagnosed females ( $N = 345$ ), 52% considered HS to be a concern for family planning. In females with both diagnosed and suspected HS ( $N = 202$ ), the most cited concerns were the uncontrolled nature of HS (59%), how HS would affect conception, the natural course of the pregnancy and childbirth (57%), the ability to breastfeed and care for the child (43%) and sexual dysfunction caused by HS (40%).

### 3.3 | The HS Patient Journey

#### 3.3.1 | Initial HS Journey

Diagnosed participants ( $N = 505$ ) reported that initial HS symptoms most frequently occurred between ages 18–31 years (45%) vs.

other age groups (Supporting Information S1: Figure S3A). Topical medications/creams (51%) and painkillers (47%) were reported by the greatest proportion of participants to alleviate initial symptoms (Supporting Information S1: Figure S3B). Pain was reported as an initial reason to seek medical help by 77% of participants (Supporting Information S1: Figure S3C).

Diagnosed participants ( $N = 505$ ) reported that it took 1.9 years to visit the first healthcare professional (HCP). Reasons for this delay included ‘not thinking it was serious/not informed it was serious’ (49%), ‘being able to cope with symptoms to begin with’ (33%), ‘was too embarrassed/ashamed’ (30%), and ‘had long waiting list to see HCP’ (17%). The HCP first visited was most frequently a general practitioner (GP; 64%) or a dermatologist (49%).

#### 3.3.2 | Diagnosis Journey

It took an average of 5.9 years from initial symptoms to a HS diagnosis (1.9 years from symptoms to first visit; 4.0 years from first visit to diagnosis) ( $N = 647$ ; 9 participants reporting onset of symptoms as their date of birth were excluded). Diagnosed participants ( $N = 505$ ) visited an average of seven different HCPs before receiving an official HS diagnosis. Overall, 33% of participants visited 0–2 HCPs, 30% visited 3–5 HCPs, 10% visited 6–7 HCPs and 28% visited  $\geq 8$  HCPs before receiving a HS diagnosis. An official HS diagnosis was most frequently provided by a dermatologist (63%); 16% reported diagnosis by a GP, and 8% by a surgeon. Overall, 35% of diagnosed participants were dissatisfied with the time to diagnosis and 26% were completely dissatisfied (score 1–3 on 10-point scale where 1 is completely dissatisfied and 10 is completely satisfied) while 39% were satisfied and 17% were completely satisfied (score 8–10 on 10-point scale).

### 3.4 | HS Treatment and Management

*Note: Tumour necrosis factor inhibitor (TNFi) drugs were the only biologic approved for this indication at the time of the study.*

In diagnosed participants ( $N = 505$ ), ongoing HS management was most frequently conducted by a dermatologist (61%) or GP (23%). Participants reported using antibiotics (36%), painkillers (33%), anti-inflammatories (33%), undergoing surgery (32%) and corticosteroids (27%) as previous treatments. Current treatments included antibiotics (48%), painkillers (32%), corticosteroids (32%), anti-inflammatories (30%) and biologics (21%), while antibiotics (28%), corticosteroids (16%) and biologics (13%) were reported as the *main* current treatment; 15% reported no current treatment (Supporting Information S1: Figure S4A,B).

Overall, 52% of diagnosed participants ( $N = 431$ ) reported that they were not satisfied with the level of control provided by their current treatment for HS; of the evaluated treatments, painkillers offered the worst level of control with 75% of 33 participants using painkillers as their main current treatment for HS reporting that they were not satisfied (Figure 5).

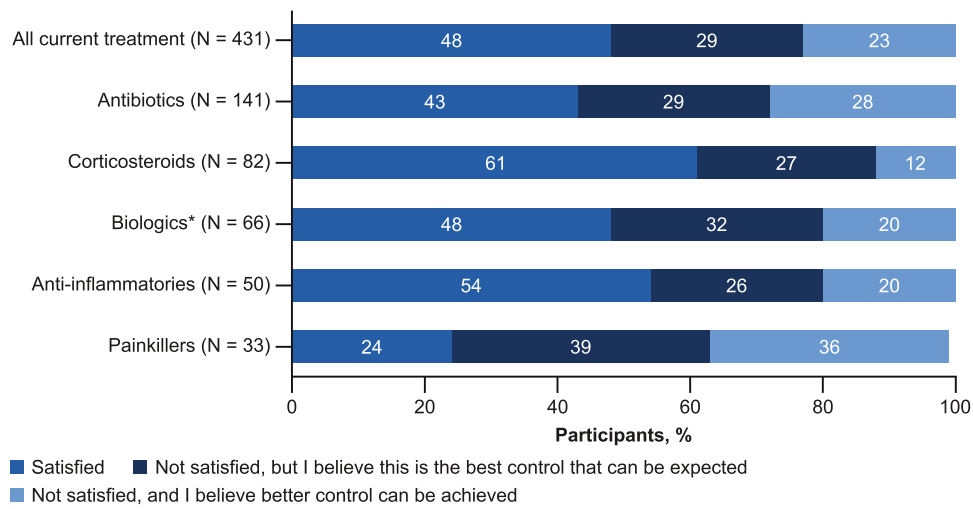


**FIGURE 5** | Level of satisfaction with current treatments according to people diagnosed with HS. \*TNFi drugs were the only biologic approved for this indication at the time of the study. Participants could be taking more than one treatment. HS, hidradenitis suppurativa; N, number of participants; TNFi, tumour necrosis factor inhibitor.

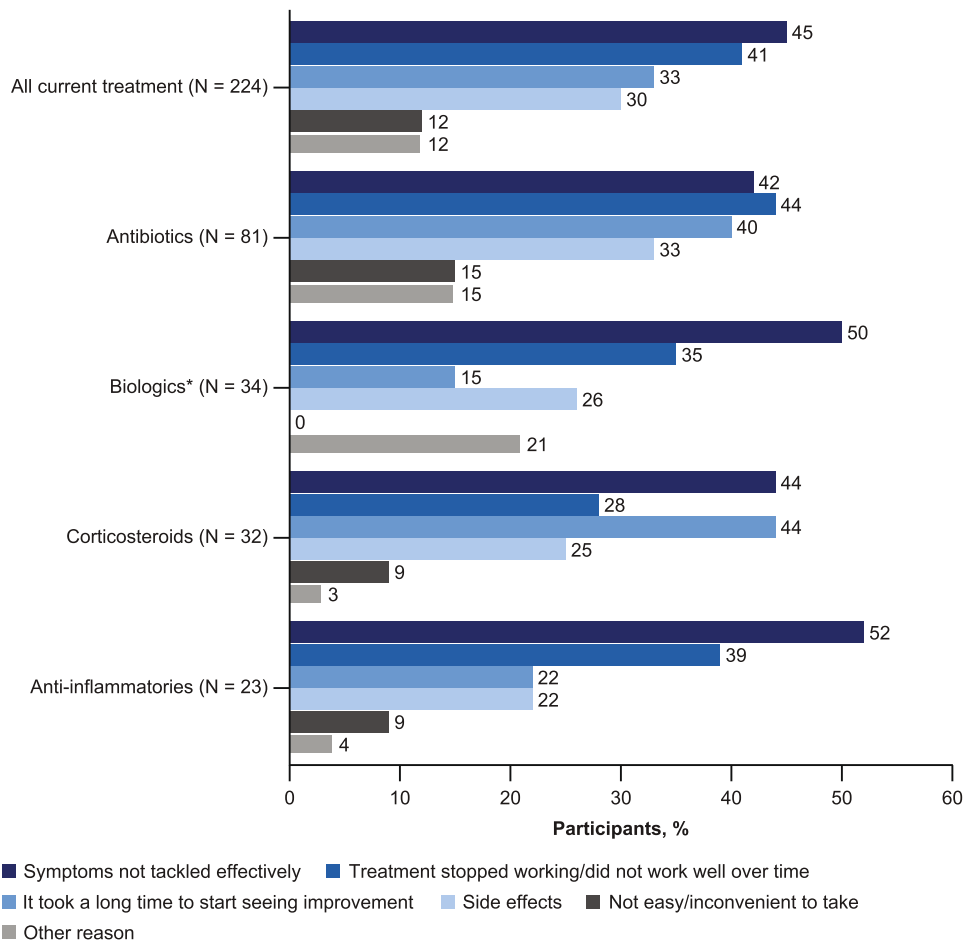


**FIGURE 6** | Reasons for dissatisfaction with main HS treatment in diagnosed participants. \*TNFi drugs were the only biologic approved for this indication at the time of the study. HS, hidradenitis suppurativa; N, number of participants; TNFi, tumour necrosis factor inhibitor.

Of 224 diagnosed participants who reported that they were not satisfied with their current treatment, 45% reported ‘symptoms were not tackled effectively’ and 41% reported that the ‘treatment stopped working/did not work well over time’ as reasons

for dissatisfaction (Figure 6). Symptoms not being tackled effectively was reported by a substantial proportion of people across main treatments (antibiotics, 42%; biologics, 50%; corticosteroids, 44%; anti-inflammatories, 52%) (Figure 6).

Overall ( $N = 656$ ), the most important desired treatment effects were 'pain relief' (58%), 'reduction of abscesses' (49%), 'QoL improvement' (47%), 'symptom relief' (itching or discomfort; 38%) and 'prevention of surgery/interventional procedures' (31%). Other desired treatment effects included 'improvement in skin appearance' (30%), 'rapid treatment effect' (29%) and 'long-lasting results' (27%).

## 4 | Discussion

The global HS Uncovered survey was conducted among people living with HS to assess patient activation, burden of disease and the patient journey. Over 60% of diagnosed participants had a PAM-13 level 3–4, indicating that they were activated and trying to gain control of their own health. Reasons for this are likely multifactorial and may include the specific features of HS, including painful lesions, often in intimate parts of the body [1, 5], the unpredictable and distressing long-term nature of HS, potential family history [25, 26], the lack of efficacious therapies, and the fact that HS is a disease that is rarely talked about, with average diagnostic delays of approximately 7–10 years [16, 17]. Further, participants with a PAM-13 score of 4 had the greatest QoL impairment, which could explain why they are most activated. Participants in the current study reported that it took on average 2 years to visit the first HCP, which is similar to a 2015 study [17], highlighting that the delay hasn't improved over the past decade. Our activation findings are broadly similar to those reported in a global survey of people with moderate to severe psoriasis [27], where around 70% of people were activated.

Despite high levels of activation, almost 70% of diagnosed participants in the current study reported that HS had 'a very large' or 'extremely large effect' on their life over the past week (per DLQI), which supports the large body of evidence that HS has a substantial negative impact on the lives of people with HS [2, 11, 28, 29]. Almost 30% of diagnosed participants in the current study reported abnormal depression while over 50% reported abnormal anxiety, which is broadly aligned with previous evidence [30–32].

HS had a major impact on work productivity, with an overall work impairment of 52% in diagnosed participants, which is similar to baseline data in a global study [29], but higher than reported in European studies [33, 34]. Further, diagnosed participants in the current study reported that they missed approximately 8 h from work over the past 7 days due to HS. Together, these results indicate that HS has implications at a wider societal and socioeconomic level.

Antibiotics were the most frequently reported main current treatment for participants in the current study, followed by corticosteroids and biologics. Over one-half of participants reported that they were not satisfied with the level of control across all current treatments. The main reason for dissatisfaction was that symptoms were not tackled properly (45%). These findings are consistent with those reported in the Global VOICE project, where 45.9% of people were dissatisfied or very dissatisfied with their current treatment, and 42.1% cited poor efficacy as a reason for dissatisfaction [2]. These results highlight the unmet need for effective treatments in HS.

Pain is a burdensome and debilitating symptom of HS [2, 28, 35, 36]. Pain relief was reported to be the most important feature of an HS treatment in the current study. The HIDradenitis Suppurativa cORE outcomes set International Collaboration (HISTORIC) identified pain, among others, as a core domain relevant to stakeholders, including patients, for use in HS clinical trials [37], which acknowledges the importance of reducing pain when considering the effectiveness of treatments.

The finding that around half of diagnosed females considered HS to be a concern for family planning was troubling, particularly given that US studies have reported that HS disproportionately affects females [8]. Almost 60% of participants in the current study reported that uncontrolled disease and concerns about how HS would affect conception, pregnancy, and childbirth had an impact on their family planning. A 2023 US study demonstrated that over 40% of respondents reported that HS made family planning more difficult [38]; the same study found high infertility rates compared to the general population.

Limitations of this study include the use of self-reported data, where information on the diagnosis or suspected diagnosis of HS were self-reported, as were treatment-related aspects, which could lead to recall bias and misinterpretation of symptoms. Participants were selected using direct-to-patient methods and online platforms, which may not capture a diverse range of people living with HS and therefore sampling bias is possible. The inclusion criteria, such as having consulted a doctor for HS and not taking part in HS surveys in the past 4 weeks, could potentially create selection bias by excluding certain patient groups, such as those with limited healthcare access or those already involved in research activities. Further, the study's scope in six countries (five for the PROM analyses) may limit how broadly its findings can be applied.

## 5 | Conclusions

HS has a large detrimental psychosocial impact on QoL, mental health, work productivity and activity, despite high activation levels among people living with HS. People with HS have positive health-seeking behaviour and are active in their care decisions, but improvements are needed in the patient journey to ensure timely diagnosis of HS and access to HCPs and effective treatments. There is an unmet need for effective treatments that provide sustained pain reduction as well as sustained improvement in work productivity.

### Author Contributions

Georgios Kokolakis, Eva Vilarrasa, Ivette Alarcon, Mei Go, Gillian Newbold, Aikaterini Mamareli, Craig Richardson, Barry M. McGrath, and Philippe Guillem made substantial contributions to conceptualization, design, validation and methodology. Ivette Alarcon, Mei Go, Gillian Newbold, and Aikaterini Mamareli were responsible for the acquisition and curation of data. Ivette Alarcon and Mei Go were responsible for project administration and resources. Gillian Newbold and Aikaterini Mamareli were responsible for formal analysis and interpretation of data. Georgios Kokolakis, Eva Vilarrasa, Amit Garg, Ivette Alarcon, Mei Go, Gillian Newbold, Aikaterini Mamareli, Craig

Richardson, Barry M. McGrath, and Philippe Guillem were responsible for writing the original draft of the article or revising and reviewing it critically for important intellectual content. All authors were responsible for the final approval of the version to be published.

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## Disclosure

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## Ethics Statement

This study complied with all applicable laws in the relevant countries regarding participant privacy. Patients completed consent forms before study participation. The study was reviewed by an independent review board (Pearl IRB Organization number 0006471) and the study was deemed exempt. The *Global Survey on Impact and Healthcare Needs* was determined by the Institutional Review Board to be Exempt according to FDA 21 CFR 56.104 and 45CFR46.104.

## Data Availability Statement

Novartis is committed to sharing with qualified external researchers, access to patient-level data and supporting clinical documents from eligible trials. These requests are reviewed and approved by an independent review panel on the basis of scientific merit. All data provided are anonymised to respect the privacy of patients who have participated in the trials in line with applicable laws and regulations.

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### Supporting Information

Additional supporting information can be found online in the Supporting Information section.