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# 348 Acronym List

- 349 Global VOICE: Global Survey Of Impact and Healthcare Needs
- 350 HS: hidradenitis suppurativa
- 351 QOL: quality of life:
- 352 HiSQOL: Hidradenitis Suppurativa Quality of Life
- 353 SES: socioecomonic status

- 354 Abstract:
- **Background:** A needs assessment for patients with hidradenitis suppurativa (HS) will support
- advancements in multidisciplinary care, treatment, research, advocacy, and philanthropy.
- **Objective:** To evaluate unmet needs from the perspective of HS patients.
- 358 Methods: Prospective multinational survey of patients between October, 2017 and July, 2018.
- **Results:** Majority (63.7%, n=827) visited a physician  $\geq$ 5 times prior to receiving formal HS diagnosis.
- 360 Mean delay in diagnosis was 10.2 years (+/- 8.9 years). Patients experienced flare daily, weekly, or
- monthly in 23.0%, 29.8%, and 31.1%, respectively. Most (61.4%, n=798) rated recent HS-related pain as
- 362 moderate or higher, while 4.5% described recent pain to be worst possible. Access to dermatology was
- rated as difficult by 37.0% (n=481). Patients reported visiting the emergency department and hospital  $\geq 5$
- times for symptoms in 18.3% and 12.5%, respectively. An extreme impact on life was reported by 43.3%
- 365 (n=563), and 14.5% were disabled due to disease. Patients reported high frequency of comorbidities, most
- 366 commonly mood disorders. Patients were dissatisfied with medical or procedural treatments in 45.9% and
- 367 34.5%, respectively.
- 368 Limitations: Data was self-reported. Patients with more severe disease may have been selected.
- 369 Conclusions: HS patients have identified several critical unmet needs that will require stakeholder
- 370 collaboration to meaningfully address.

#### 371 Introduction

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372 Hidradenitis suppurativa (HS), also known as acne inversa, is a potentially debilitating 373 inflammatory disease that is linked to significant comorbidity burden<sup>1</sup> and overall mortality,<sup>1-3</sup> and that is also known to have substantial impact on general health-related and skin-specific quality of life (OOL).<sup>4,5</sup> 374 375 Its inherent unpredictability with respect to disease course and treatment response poses challenges for patients and physicians. The purpose of the Global Survey Of Impact and Healthcare Needs (Global 376 377 VOICE) project was to evaluate unmet needs in HS from the perspective of patients with the goal of 378 supporting awareness initiatives in public and medical sectors, multidisciplinary approaches to care, 379 advances in treatment, development of the research agenda, as well advocacy and philanthropy efforts. Methods 380 381 Global affiliates from 27 institutions, most of which were HS referral centers, in 14 countries 382 across four continents agreed to prospective recruitment of participants between October, 2017 and July, 2018. All patients at the center were offered an opportunity to participate, and there was no selection for 383 384 disease stage. The questionnaire distributed to participants was developed by content experts and by 385 patients with the disease in their capacity as research partners. It comprised 50 questions designed to 386 capture demographics, perspectives on diagnosis and care, pain and symptoms, life impact, comorbid conditions, and treatment. Life impact was assessed using a disease-specific QOL instrument called the 387 Hidradenitis Suppurativa Quality of Life instrument (HiSQOL).<sup>5,6</sup> This study received approval from the 388 389 human subjects committee of the Feinstein Institute for Medical Research at Northwell Health. 390 Statistical Analysis

There were 1,927 surveys returned, of which 1,299 surveys met inclusion criteria of being completed by a patient diagnosed with HS by a licensed healthcare provider and having a response to all variables of interest. Complete case analysis was performed. Categorical variables were described as frequencies and percentages, while means (standard deviation) were used to describe continuous variables. We assessed association between self-reported delay in diagnosis and age using ANOVA.

396 **Results** 

397 Patient Characteristics

Characteristics of Global VOICE participants are described in Table I. Participants were mostly
 from Europe (55.4%) and North America (38.0%), and were mostly aged less than 40 years (61.3%),

400 female (84.9%), and white (80.6%). Participants looking for work reported being unemployed in 9.6% of

401 cases, and another 14.5% reported being disabled and unable to work due to HS.

### 402 Diagnosis and Care

403 Mean age at onset of symptoms was 20.5 (+/- 9.3) years while mean age at diagnosis was 30.7

404 (+/- 10.9) years. Mean delay from onset of symptoms to diagnosis was 10.2 years (+/- 8.9 years). The

405 majority of participants visited a physician for symptoms  $\geq 5$  times (63.7%, n=827) or 3-4 times (17.4%,

406 n=226) prior to receiving a formal HS diagnosis. For 54.4% of participants (n=707), diagnosis was made

407 by a dermatologist. For 59.8% (n=777) of participants, a dermatologist was the main physician managing

408 their HS. However, 37.0% (n=481) of participants rated access to their dermatologist as difficult or very

409 difficult. For symptoms related to HS, participants reported visiting the emergency department >5 times

410 (18.3%, n=238), 4-5 times (7.7%, n=100), 2-3 times (17.2%, n=224), and once (16.3%, n=212).For

411 symptoms related to HS, participants reported having been hospitalized >5 times (12.5%, n=163), 4-5

412 times (4.5%, n=59), 2-3 times (11.5%, n=149), and once (15.9%, n=206).

413 *Pain and Symptoms* 

414 On the Numeric Rating Scale (NRS) for pain, 61.4% (n=798) of participants rated HS-related

415 pain over the past week as moderate or higher (NRS score  $\geq$ 5). Participants described worst possible pain

416 (NRS score 10) in 4.5% (n=59) of cases. Only 9.0% (n=117) of participants described no pain (NRS score

- 417 0) over the past week. Mean NRS score 5.0 (SD=2.8).
- 418 Participants also described the following symptoms related to HS over the past week: drainage
- 419 (71.8%, n=933); odor (53.8%, n=699), and fatigue (61.0%, n=793). A flare was experienced daily

420 (23.0%, n=299), weekly (29.8%, n=387), or monthly (31.1%, n=404) in most participants.

421 Life Impact

16

- Table II lists items and corresponding impact on QOL for participants. Most participants
- reported that HS impacted their lives moderately (27.2%, n=353) or very much/extremely (43.3%, n=563)
  in the past week.

425 *Comorbid Conditions* 

- 426 Comorbid conditions among participants are described in **Table III**. Anxiety (36.2%) and
- 427 depression (35.8%) were most frequently reported. Some other notable comorbid conditions reported
- 428 were suicidal ideation or attempt (9.1%), infertility (5.7%), spondyloarthritis (5.5%), inflammatory bowel

diseases (5.3%), substance abuse (3.6%), and sexual dysfunction (3.5%).

430 Treatment

422

431 Participants were dissatisfied or very dissatisfied with current treatment in 45.9% (n=596) of

432 cases. Among those dissatisfied, reasons for dissatisfaction included poor efficacy (42.1%, n=547),

433 undesirable side effects (18.9%, n=246), expense (10.5%, n=136), inconvenience (10.2%, n=132), and

434 invasiveness (7.5%, n=98). With respect to procedural treatments, 29.3% (n=380) of participants reported

435 feeling satisfied or very satisfied, while 34.6% (n=449) reported feeling dissatisfied or very dissatisfied.

436 Level of optimism for having satisfactory control of symptoms within the next 3 months was low or very437 low in 45.9% (n=596).

- 438 **Table IV** describes frequency of medical and procedural treatment among participants. Most
- 439 frequent medical treatments included oral antibiotics (85.6%, n=1,112) and intralesional corticosteroid

440 (24.9%, n=323). Participants used a biologic in 20.8% (n=270) of cases, with adalimumab being the most

441 frequent (16.0%, n=208). Participants used anti-androgen therapy in 12.7% (n=165) of cases, with

- spironolactone being the most frequent (11.1%, n=144). An oral retinoid and traditional
- immunosuppressive medication was used by 14.1% (n=183) and 8.7% (n=113) of participants,
- respectively. Participants underwent procedural treatment in 82.8% (n=1,075) of cases. Most frequent
- 445 procedures were incision and drainage (70.0%, n=909), excision (54.8%, n=712), laser hair removal
- 446 (10.5%, n=136), and deroofing (9.0%, n=117).
- 447 Discussion

To the best of the authors' knowledge, the analysis presented herein represents the largest and most comprehensive multinational study of patient perspectives on unmet needs in HS. A number of disease-related observations warrant discussion.

451 While nearly all Global VOICE patients had at least high school level education, approximately 10% were unable to find work. Approximately 15% also reported being disabled and unable to work due 452 to their disease. Previous cohort studies have described frequent absences from work and inability to 453 properly perform responsibilities, in some cases resulting in unemployment,<sup>7-9</sup> and this has also result in a 454 negative impact on personal finances.8 Indeed, HS patients were more often observed to have low 455 socioeconomic status (SES) in recent population studies.<sup>10,11</sup> While low SES may influence development 456 457 of disease, the more likely directional relationship is that low SES, potentially by way of inability to 458 acquire or maintain gainful employment, is a disease consequence. Direct and indirect socioeconomic 459 impact of HS warrants further study.

Most patients visited a physician at least five times prior to receiving a diagnosis, and they 460 461 experienced on average a 10-year delay to diagnosis. Diagnosis delay reported herein is substantially longer than a mean delay of 7.2 years which was observed in a previous multinational survey.<sup>12</sup> 462 463 Dermatologists likely have an important role in reducing diagnosis delay in HS, and indeed a dermatologist ultimately provided the formal diagnosis for over half of patients in this analysis. A 464 465 dermatologist was also the main physician managing the disease in approximately 60% of patients. Care 466 by a dermatologist has been shown to provide greatest likelihood of initiating medical treatment for HS, as well as for escalating therapy over time.<sup>13</sup> However, overall utilization of ambulatory dermatology 467 468 encounters appears low, as only one in five HS patients in the US has an established relationship with a dermatologist.<sup>14</sup> Notably, half also reported disease flares either daily or weekly, and more than 80% 469 experienced flares at least monthly. And yet, more than one third rated access to a dermatologist as 470 difficult or very difficult, despite most living in urban or suburban areas. Not surprisingly then, one in 471 four and one in six patients also reported visiting the emergency department and having been hospitalized, 472 473 respectively, at least 4-5 times for acute symptoms. Utilization of acute care facilities, for which disease-

specific costs are high,<sup>15-18</sup> may be reduced further with improved urgent access to dermatologists. Along
with communicating the value of dermatologists in diagnosis as well as acute and ongoing management
of HS, there may be a need to ensure timely access to a dermatologist with the goal of improving quality
and cost of care.

478 In an international delphi exercise to define the core outcome set for clinical trials in HS, patients selected pain as their most important symptom.<sup>19</sup> Remarkably, nine in ten Global VOICE patients 479 described recent pain associated with their disease, while six in ten rated this pain as moderate to worst 480 481 possible. In another study, recent pain was reported by 77.5% of patients and was linked to a substantial decrease in QOL.<sup>20</sup> Specifically, pain and discomfort have been shown to interfere with daily activities, 482 work, school or leisure, and result in feelings of helplessness and dependency.<sup>21</sup> Chronicity of pain may 483 484 also be a significant factor related to misuse of substances, which was reported by approximately 4% of 485 Global VOICE patients. In a previous population analysis, prevalence of substance use disorder among HS patients was also observed to be 4%.<sup>22</sup> However, strategies for addressing HS-associated pain are not 486 487 well established. If pain is addressed at all, there is likely to exist variations in pain management practices,<sup>23-25</sup> which may contribute to substance abuse among HS patients. Development of appropriate 488 489 and effective pain management strategies for HS patients represents a fundamental unmet need. The 490 authors underscore that observations on substance abuse in this study should not further stigmatize 491 patients who are afflicted with HS. Rather, our hope is that the medical community, including 492 dermatologists, will further embrace and engage integrated care plans which comprehensively support 493 their needs.

In this analysis, a significant proportion of HS patients described a moderate to extreme, overall and domain specific impact on life related to disease. Our population assessment of life impact is supported further through detailed qualitative assessment within tertiary-center cohorts in which HS patients describe impairments in enjoyment and satisfaction with general activity; independence; selfesteem and body image, stigmatization and isolation,<sup>6,7,21,26-30</sup> as well as feelings of self-consciousness, embarrassment, shame, repulsion, or being unlovable related to malodorous drainage or visible areas of involvement.<sup>31</sup> Given the many ways the disease impacts QOL, it is not surprising that disease-related life impact appears to be more significant for HS patients compared to those with atopic dermatitis, psoriasis, acne vulgaris, alopecia, among other disorders of the integument.<sup>26,32-37</sup> In consideration for the total wellbeing of HS patients, evaluation and management should include addressing psychosocial aspects of the disease through interdisciplinary care with behavioral health professionals who can address mental health issues and support coping and resilience strategies.<sup>38,39</sup>

506 More than 80% of Global VOICE patients report having a comorbid condition. This observation 507 is supported by a growing body of literature which suggests that HS, as a chronic inflammatory disease, 508 may represent a bridge to comorbid illnesses. In a recent analysis, HS patients were observed to have 509 twice the overall comorbidity burden compared with patients who did not have HS, as well as a 510 significantly greater burden compared to psoriasis patients.<sup>1</sup>HS is thought to have similar comorbidity 511 burden to other systemic diseases including systemic lupus erythematosus, dermatomyositis, ankylosing 512 spondylitis, and rheumatoid arthritis.<sup>1</sup> Patients with HS who have Charlson Comorbidity Index (CCI) of at 513 least 5 had approximately five times the risk of 5-year mortality compared to those with CCI score of 514 zero.

With more than one in three patients reporting depression and/or anxiety, mood disorders 515 represented the most frequent comorbidity among Global VOICE patients. Prevalence of depression 516 within HS cohorts at referral centers ranges between 19.5% and 41.6%.<sup>26,40-42</sup> Population data exploring 517 the association between HS and depression also indicates a significant burden of mood disorder.<sup>43-45</sup> 518 519 Notably, approximately one in eleven patients in the current analysis also reported suicidal ideation or 520 attempt, which represents an alarmingly high frequency, especially in the context of a known association between HS and completed suicide.<sup>46</sup>Mood disorders and suicidality among HS patients is likely 521 explained by the physical and psychosocial effects of the disease which result in poor QOL and low 522 523 optimism. Global VOICE patients described a number of additional comorbidities, which are further supported by other population-based analyses, including acne,<sup>47</sup> polycystic ovarian syndrome,<sup>48</sup> pyoderma 524

gangranosum,<sup>49</sup> inflammatory bowel disease,<sup>50-52</sup> lymphomas,<sup>53</sup> spondyloarthritis,<sup>54</sup> metabolic disease,<sup>55-59</sup>
obstructive sleep apnea,<sup>60</sup> major adverse cardiac events,<sup>3</sup> sexual dysfunction,<sup>61</sup> substance abuse and
chronic opioid use,<sup>22,62</sup> and Down syndrome.<sup>63</sup> Given a general lack of disease awareness in HS and of its
comorbidities in medical communities, dermatologists may need to be proactive in making
recommendations on relevant preventative and screening measures to interdisciplinary care teams.

Nearly half of Global VOICE patients were dissatisfied with current treatments, most commonly 530 531 because of perceived poor efficacy and undesirable side effects. One third was also dissatisfied with 532 procedural treatments. Thus, it is not surprising that nearly half of patients expressed low optimism for 533 having satisfactory control of symptoms in the near future. There is however growing enthusiasm in the medical community for addressing treatment as a fundamental unmet need in HS. Recent investigative 534 535 efforts to understand pathogenesis in HS, including immunologic aberrations,<sup>64,65</sup> genetic predispositions,<sup>66</sup> and microbiome alteration<sup>67,68</sup> have translated to therapeutic trials which show promise. 536 The National Institute of Health's database of clinical studies (accessible at www.Clinicaltrials.gov) 537 538 describes 19 active or planned medical and procedural interventional trials in February, 2019. In alignment with drug development programs, there is also an international initiative to develop a core set 539 540 of measures for trials in HS with the goal of improving measurement of disease activity and treatment response, as well as of comparing therapeutic effectiveness. To date, Hidradenitis Suppurativa Core 541 542 Outcome Set Collaboration (HISTORIC), a section of the International Dermatology Outcome Measures 543 (IDEOM) organization that is further supported by the department of dermatology at Zealand University 544 Hospital and the Cochrane Skin Core Outcomes Set Initiative (CS-COUSIN), has reached global stakeholder consensus on the core set of domains for HS trials,<sup>69</sup> and is working toward finalizing its core 545 546 measures set, which include new instruments under development. Additionally, there are several searchable global medical and advocacy organizations in HS that facilitate peer-to-peer support, 547 548 encourage scientific discovery, and support access to treatments.

There are important limitations to this analysis warranting consideration. Data was self-reported and may be subject to misinterpretation of questions and to recall bias. Since questionnaires were administered through dermatology centers, patients with more active or severe disease may have been selected. While demographic characteristics of the surveyed cohort approximate those of other HS populations in North America and Europe,<sup>43,70-72</sup> our sample is non-random and uncontrolled. As such, results with modest directionality may be difficult to interpret. Complete case analysis has the potential to bias results when patients with missing data differ systematically from patients without missing data. However, analysis of missing data among survey participants showed that patients excluded due to any missing data had similar characteristics and responses to patients included in the analysis.

Through this study, we have augmented our understanding of existing needs for HS patients, and we have identified several unmet needs which require attention. Addressing unmet needs in HS (**Table V**) is likely to necessitate a shared vision of health for HS patients among all stakeholders including patients, experts, interdisciplinary physicians, scientists, industry, regulatory agencies, philanthropists, advocates, and policy makers.

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Demographics	n (%)
Age	
18-30 years	368 (28.3)
31-40 years	428 (33.0)
41-50 years	317 (24.4)
51-60 years	151 (11.6)
61+ years	35 (2.7)
Gender	
Male	196 (15.1)
Female	1103 (84.9)
Race (US, Canada only, $n=479$ )	
White	386 (80.6)
Black	65 (13.6)
Other	28 (5.8)
Body Mass Index*	
Underweight or Normal Weight (BMI <24.9)	269 (20.7)
Overweight (BMI 25.0-29.9)	306 (23.6)
Obese (BMI $\geq$ 30.0)	724 (55.7)
Tobacco Smoking Status	
Active smoker	571 (44.0)
Former smoker	352 (27.1)
Never a smoker	376 (28.9)
Highest Education Level Achieved	
High school	464 (35.7)
College/university degree	550 (42.3)
Graduate school degree	210 (16.2)
None of the above	75 (5.8)
Employment Status	
Employed/Not looking for employment/Retired	985 (75.8)
Not employed, looking for work	125 (9.6)
Disabled, not able to work	189 (14.5)
Marital Status	
Single/Divorced	419 (32.3)
In a relationship/Married/Widowed	880 (67.7)
Region	· /
Europe	719 (55.4)
North America	493 (38.0)
Other <sup>a</sup>	87 (6.7)
Setting	· /
Urban	629 (48.4)
Suburban	338 (26.0)
Rural	332 (25.6)
Physician diagnosing HS	()
Dermatologist	707 (54 4)
Primary care	265 (20.4)
Surgeon	141 (10.9)
Obstetrician/Gynecologist	61 (4 7)
Acute care physician (Emergency Medicine or Hospitalist	54 (4 2)
Other type of physician	51(1.2) 53 (4.1)

738 Table I: Demographics and Clinical Characteristics of Global VOICE participants (N=1,299)

Pediatrician	11 (0.8)
Endocrinologist	4 (0.3)
Urologist	3 (0.2)

740

HS- hidradenitis suppurativa a – Includes Asia, Australia, Africa, and South America \* Body Mass Index calculated from self-reported height and weight 

	Not relevant	Not at all/slightly	Moderately	Very much /	Cannot engage
In the next one work how much has your US				Extremely	
In the past one week, now much has your HS					
Wolling	72 (5 5)	720(554)	250(10.0)	227 (17.5)	(1, 6)
waiking	72 (5.5)	720 (55.4)	259 (19.9)	227 (17.5)	21 (1.0)
Reaching	243 (18.7)	745 (57.4)	123 (9.5)	173 (13.3)	15 (1.2)
Standing up	125 (9.6)	851 (65.5)	185 (14.2)	133 (10.2)	5 (0.4)
Sitting down	73 (5.6)	651 (50.1)	253 (19.5)	308 (23.7)	14 (1.1)
Sleeping	64 (4.9)	679 (52.3)	252 (19.4)	292 (22.5)	12 (0.9)
Laying down	74 (5.7)	820 (63.1)	213 (16.4)	189 (14.5)	3 (0.2)
Leisure	93 (7.2)	496 (38.2)	230 (17.7)	348 (26.8)	132 (10.2)
Toilet	99 (7.6)	823 (63.4)	180 (13.9)	196 (15.1)	1 (0.1)
Shower	58 (4.5)	735 (56.6)	245 (18.9)	258 (19.9)	3 (0.2)
Dressed	53 (4.1)	726 (55.9)	224 (17.2)	290 (22.3)	6 (0.5)
Hair removal	205 (15.8)	388 (29.9)	164 (12.6)	336 (25.9)	206 (15.9)
Antiperspirant	236 (18.2)	587 (45.2)	112 (8.6)	193 (14.9)	171 (13.2)
Getting around	88 (6.8)	735 (56.6)	202 (15.6)	239 (18.4)	35 (2.7)
Exercising	143 (11.0)	444 (34.2)	193 (14.9)	326 (25.1)	193 (14.9)
Housework	71 (5.5)	624 (48.0)	232 (17.9)	336 (25.9)	36 (2.8)
Providing care	316 (24.3)	583 (44.9)	156 (12.0)	207 (15.9)	37 (2.8)
In the past one week, how much has your HS:	× /	. ,			
Influenced your ability to work or study	159 (12.2)	606 (46.7)	181 (13.9)	274 (21.1)	79 (6.1)
Limited the type of work or study you do	175 (13.5)	623 (48)	153 (11.8)	275 (21.2)	73 (5.6)
Decreased the amount of time you spent on					
work or study	185 (14.2)	643 (49.5)	155 (11.9)	253 (19.5)	63 (4.8)
Caused you to use extra effort to do your					
work or study	174 (13.4)	604 (46.5)	144 (11.1)	319 (24.6)	58 (4.5)
In the past one week, how have your current or					
potential new HS lesions influenced:					
Clothing choice to avoid discomfort	38(2.9)	311 (23.9)	207 (15.9)	743 (57.2)	N/A
Clothing choice to avoid visibility				()	N/A
of HS	101 (7.8)	463 (35.6)	141 (10.9)	594 (45 7)	
Clothing choice to avoid an HS	101 (1.0)	100 (0010)	(10.7)		N/A
Flare	54 (4 2)	383 (29 5)	193 (14 9)	669 (51 5)	1 1/2 1
In the past one week, how bothered have you	····	200 (1).0)			

 Table II: Disease-related Quality of Life Impact Among Global VOICE Participants (N=1299)

Pain       18 (1.4)       446 (34.3)       315 (24.2)       520 (40.0)       N/A         Fatigue       58 (4.5)       462 (35.6)       276 (21.2)       503 (38.7)       N/A         Itch       39 (3.0)       526 (40.5)       303 (23.3)       431 (33.2)       N/A         Drainage       39 (3.0)       523 (40.3)       307 (23.6)       430 (33.1)       N/A         Drainage       39 (3.0)       523 (40.3)       307 (23.6)       430 (33.1)       N/A         Odor       44 (3.4)       697 (53.7)       228 (17.6)       330 (25.4)       N/A         Skin tightness       48 (3.7)       554 (42.6)       268 (20.6)       429 (33.0)       N/A         Red lumps or knots       25 (1.9)       319 (24.6)       301 (23.2)       654 (50.3)       N/A         In the past one week, how much has your HS       250 (1.9)       319 (24.6)       301 (23.2)       654 (50.3)       N/A         Irritable       50 (3.8)       568 (43.7)       226 (17.4)       455 (35.0)       N/A         Angry       57 (4.4)       610 (47.0)       211 (16.2)       421 (32.4)       N/A         Irritable       55 (4.2)       578 (44.5)       225 (17.3)       441 (33.9)       N/A         Irritable<	been by these HS symptoms:					
Fatigue58 (4.5)462 (35.6)276 (21.2)503 (38.7)N/AItch39 (3.0)526 (40.5)303 (23.3)431 (33.2)N/ADrainage130 (10.0)898 (69.1)144 (11.1)127 (9.8)N/ADrainage39 (3.0)523 (40.3)307 (23.6)430 (33.1)N/AOdor44 (3.4)697 (53.7)228 (17.6)330 (25.4)N/ASkin tightness48 (3.7)554 (42.6)268 (20.6)429 (33.0)N/ARed lumps or knots25 (1.9)319 (24.6)301 (23.2)654 (50.3)N/AIn the past one week, how much has your HS25 (1.9)319 (24.6)211 (16.2)421 (32.4)N/AAngry57 (4.4)610 (47.0)211 (16.2)421 (32.4)N/AEmbarrassed69 (5.3)532 (41.0)213 (16.4)485 (37.3)N/AIrritable55 (4.2)578 (44.5)225 (17.3)441 (33.9)N/AInthe past one week, how much has HS569 (60)605 (46.6)204 (15.7)401 (30.9)N/AIndicate one week, how much has HS569 (60)605 (46.6)204 (15.7)401 (30.9)N/ALonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HS177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)<	Pain	18 (1.4)	446 (34.3)	315 (24.2)	520 (40.0)	N/A
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	Fatigue	58 (4.5)	462 (35.6)	276 (21.2)	503 (38.7)	N/A
Flu-like130 (10.0)898 (69.1)144 (11.1)127 (9.8)N/ADrainage39 (3.0)523 (40.3)307 (23.6)430 (33.1)N/AOdor44 (3.4)697 (53.7)228 (17.6)330 (25.4)N/AOding48 (3.7)554 (42.6)268 (20.6)429 (33.0)N/ARed lumps or knots25 (1.9)319 (24.6)301 (23.2)654 (50.3)N/AIn the past one week, how much has your HS25 (1.9)319 (24.6)301 (23.2)654 (50.3)N/APepressed50 (3.8)568 (43.7)226 (17.4)455 (35.0)N/AAngry57 (4.4)610 (47.0)211 (16.2)421 (32.4)N/AEmbarrassed69 (5.3)532 (41.0)213 (16.4)485 (37.3)N/AIrritable55 (4.2)578 (44.5)225 (17.3)441 (33.9)N/ALonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HS177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/AImpacted your concentration (i.e., leisure, school or work):N/A676 (52.0)298 (22.9)325 (25.0)N/AImpacted your life:N/A676 (52.0)298 (22.9)325	Itch	39 (3.0)	526 (40.5)	303 (23.3)	431 (33.2)	N/A
Drainage         39 (3.0)         523 (40.3)         307 (23.6)         430 (33.1)         N/A           Odor         44 (3.4)         697 (53.7)         228 (17.6)         330 (25.4)         N/A           Skin tightness         48 (3.7)         554 (42.6)         268 (20.6)         429 (33.0)         N/A           Red lumps or knots         25 (1.9)         319 (24.6)         301 (23.2)         654 (50.3)         N/A           In the past one week, how much has your HS         25 (1.9)         319 (24.6)         301 (23.2)         654 (50.3)         N/A           Caused you to feel:         Depressed         50 (3.8)         568 (43.7)         226 (17.4)         455 (35.0)         N/A           Angry         57 (4.4)         610 (47.0)         211 (16.2)         421 (32.4)         N/A           Embarrassed         69 (5.3)         532 (41.0)         213 (16.4)         485 (37.3)         N/A           Irritable         55 (4.2)         578 (44.5)         225 (17.3)         441 (33.9)         N/A           Lonely         91 (7.0)         713 (54.9)         154 (11.9)         341 (26.3)         N/A           Mithrawn         77 (5.9)         422 (32.5)         169 (13.0)         431 (48.6)         N/A           In t	Flu-like	130 (10.0)	898 (69.1)	144 (11.1)	127 (9.8)	N/A
Odor         44 (3.4)         697 (53.7)         228 (17.6)         330 (25.4)         N/A           Skin tightness         48 (3.7)         554 (42.6)         268 (20.6)         429 (33.0)         N/A           Red lumps or knots         25 (1.9)         319 (24.6)         301 (23.2)         654 (50.3)         N/A           In the past one week, how much has your HS         caused you to feel:         50 (3.8)         568 (43.7)         226 (17.4)         455 (35.0)         N/A           Depressed         50 (3.8)         568 (43.7)         226 (17.4)         455 (35.0)         N/A           Angry         57 (4.4)         610 (47.0)         211 (16.2)         421 (32.4)         N/A           Embarrassed         69 (5.3)         532 (41.0)         213 (16.4)         485 (37.3)         N/A           Irritable         55 (4.2)         578 (44.5)         225 (17.3)         441 (33.9)         N/A           Lonely         91 (7.0)         713 (54.9)         154 (11.9)         341 (26.3)         N/A           Withdrawn         77 (5.9)         422 (32.5)         169 (13.0)         631 (48.6)         N/A           In the past one week, how much has HS         impacted your sexual activity:         Lack of desire         171 (13.6)         354 (27.3)	Drainage	39 (3.0)	523 (40.3)	307 (23.6)	430 (33.1)	N/A
Skin tightness         48 (3.7)         554 (42.6)         268 (20.6)         429 (33.0)         N/A           Red lumps or knots         25 (1.9)         319 (24.6)         301 (23.2)         654 (50.3)         N/A           In the past one week, how much has your HS         25 (1.9)         319 (24.6)         301 (23.2)         654 (50.3)         N/A           Depressed         50 (3.8)         568 (43.7)         226 (17.4)         455 (35.0)         N/A           Angry         57 (4.4)         610 (47.0)         211 (16.2)         421 (32.4)         N/A           Embarrassed         69 (5.3)         532 (41.0)         213 (16.4)         485 (37.3)         N/A           Irritable         55 (4.2)         578 (44.5)         225 (17.3)         441 (33.9)         N/A           Anxious         89 (6.9)         605 (46.6)         204 (15.7)         401 (30.9)         N/A           Lonely         91 (7.0)         713 (54.9)         154 (11.9)         341 (26.3)         N/A           Withdrawn         77 (5.9)         422 (32.5)         169 (13.0)         631 (48.6)         N/A           In the past one week, how much has HS         impacted your sexual activity:         Impacted your sexual activity:         Impacted your (31.3)         130 (10.0)	Odor	44 (3.4)	697 (53.7)	228 (17.6)	330 (25.4)	N/A
Red lumps or knots       25 (1.9)       319 (24.6)       301 (23.2)       654 (50.3)       N/A         In the past one week, how much has your HS       caused you to feel:                N/A         Angry       57 (4.4)       610 (47.0)       211 (16.2)       421 (32.4)       N/A         Embarrassed       69 (5.3)       532 (41.0)       213 (16.4)       485 (37.3)       N/A         Irritable       55 (4.2)       578 (44.5)       225 (17.3)       441 (33.9)       N/A         Anxious       89 (6.9)       605 (46.6)       204 (15.7)       401 (30.9)       N/A         Lonely       91 (7.0)       713 (54.9)       154 (11.9)       341 (26.3)       N/A         Withdrawn       77 (5.9)       422 (32.5)       169 (13.0)       631 (48.6)       N/A         In the past one week, how much has HS       impacted your sexual activity:          138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A <td>Skin tightness</td> <td>48 (3.7)</td> <td>554 (42.6)</td> <td>268 (20.6)</td> <td>429 (33.0)</td> <td>N/A</td>	Skin tightness	48 (3.7)	554 (42.6)	268 (20.6)	429 (33.0)	N/A
In the past one week, how much has your HS caused you to feel:       Depressed       50 (3.8)       568 (43.7)       226 (17.4)       455 (35.0)       N/A         Angry       57 (4.4)       610 (47.0)       211 (16.2)       421 (32.4)       N/A         Embarrassed       69 (5.3)       532 (41.0)       213 (16.4)       485 (37.3)       N/A         Irritable       55 (4.2)       578 (44.5)       225 (17.3)       441 (33.9)       N/A         Anxious       89 (6.9)       605 (46.6)       204 (15.7)       401 (30.9)       N/A         Lonely       91 (7.0)       713 (54.9)       154 (11.9)       341 (26.3)       N/A         Withdrawn       77 (5.9)       422 (32.5)       169 (13.0)       631 (48.6)       N/A         In the past one week, how much has HS impacted your sexual activity:       Lack of desire       171 (13.2)       407 (31.3)       130 (10.0)       453 (34.9)       138 (10.6)         Embarrassment       177 (13.6)       354 (27.3)       138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A <tr< td=""><td>Red lumps or knots</td><td>25 (1.9)</td><td>319 (24.6)</td><td>301 (23.2)</td><td>654 (50.3)</td><td>N/A</td></tr<>	Red lumps or knots	25 (1.9)	319 (24.6)	301 (23.2)	654 (50.3)	N/A
caused you to feel:Depressed $50 (3.8)$ $568 (43.7)$ $226 (17.4)$ $455 (35.0)$ N/AAngry $57 (4.4)$ $610 (47.0)$ $211 (16.2)$ $421 (32.4)$ N/AEmbarrassed $69 (5.3)$ $532 (41.0)$ $213 (16.4)$ $485 (37.3)$ N/AIrritable $55 (4.2)$ $578 (44.5)$ $225 (17.3)$ $441 (33.9)$ N/AAnxious $89 (6.9)$ $605 (46.6)$ $204 (15.7)$ $401 (30.9)$ N/ALonely $91 (7.0)$ $713 (54.9)$ $154 (11.9)$ $341 (26.3)$ N/AWithdrawn $77 (5.9)$ $422 (32.5)$ $169 (13.0)$ $631 (48.6)$ N/AIn the past one week, how much has HSimpacted your sexual activity:Impacted your sexual activity:Impacted your sexual activity:Lack of desire $171 (13.2)$ $407 (31.3)$ $130 (10.0)$ $453 (34.9)$ $138 (10.6)$ Embarrassment $177 (13.6)$ $354 (27.3)$ $138 (10.6)$ $529 (40.7)$ $101 (7.8)$ Pain $187 (14.4)$ $437 (33.6)$ $144 (11.1)$ $427 (32.9)$ $104 (8.0)$ In the past one week, how much has your HSN/A $676 (52.0)$ $298 (22.9)$ $325 (25.0)$ N/Aimpacted your concentration (i.e., leisure, school or work):In the past one week, how much has your HSN/A $383 (29.5)$ $353 (27.2)$ $563 (43.3)$ N/A	In the past one week, how much has your HS					
Depressed $50 (3.8)$ $568 (43.7)$ $226 (17.4)$ $455 (35.0)$ N/AAngry $57 (4.4)$ $610 (47.0)$ $211 (16.2)$ $421 (32.4)$ N/AEmbarrassed $69 (5.3)$ $532 (41.0)$ $213 (16.4)$ $485 (37.3)$ N/AIrritable $55 (4.2)$ $578 (44.5)$ $225 (17.3)$ $441 (33.9)$ N/AAnxious $89 (6.9)$ $605 (46.6)$ $204 (15.7)$ $401 (30.9)$ N/ALonely $91 (7.0)$ $713 (54.9)$ $154 (11.9)$ $341 (26.3)$ N/AWithdrawn $77 (5.9)$ $422 (32.5)$ $169 (13.0)$ $631 (48.6)$ N/AIn the past one week, how much has HSimpacted your sexual activity:If $171 (13.2)$ $407 (31.3)$ $130 (10.0)$ $453 (34.9)$ $138 (10.6)$ Embarrassment $177 (13.6)$ $354 (27.3)$ $138 (10.6)$ $529 (40.7)$ $101 (7.8)$ Pain $187 (14.4)$ $437 (33.6)$ $144 (11.1)$ $427 (32.9)$ $104 (8.0)$ In the past one week, how much has your HSN/A $676 (52.0)$ $298 (22.9)$ $325 (25.0)$ N/Aimpacted your concentration (i.e., leisure, school or work):In the past one week, how much has your HSN/A $383 (29.5)$ $353 (27.2)$ $563 (43.3)$ N/A	caused you to feel:					
Angry57 (4.4)610 (47.0)211 (16.2)421 (32.4)N/AEmbarrassed69 (5.3)532 (41.0)213 (16.4)485 (37.3)N/AIrritable55 (4.2)578 (44.5)225 (17.3)441 (33.9)N/AAnxious89 (6.9)605 (46.6)204 (15.7)401 (30.9)N/ALonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HSimpacted your sexual activity:Lack of desire171 (13.2)407 (31.3)130 (10.0)453 (34.9)138 (10.6)Embarrassment177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/Aimpacted your concentration (i.e., leisure, school or work):In the past one week, how much has your HSN/A383 (29.5)353 (27.2)563 (43.3)N/Aimpacted your life:171144383 (29.5)353 (27.2)563 (43.3)N/A	Depressed	50 (3.8)	568 (43.7)	226 (17.4)	455 (35.0)	N/A
Embarrassed69 (5.3)532 (41.0)213 (16.4)485 (37.3)N/AIrritable55 (4.2)578 (44.5)225 (17.3)441 (33.9)N/AAnxious89 (6.9)605 (46.6)204 (15.7)401 (30.9)N/ALonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HSimpacted your sexual activity:Lack of desire171 (13.2)407 (31.3)130 (10.0)453 (34.9)138 (10.6)Embarrassment177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/Aimpacted your concentration (i.e., leisure, school or work):N/A383 (29.5)353 (27.2)563 (43.3)N/Aimpacted your life:1111111111111111	Angry	57 (4.4)	610 (47.0)	211 (16.2)	421 (32.4)	N/A
Irritable $55 (4.2)$ $578 (44.5)$ $225 (17.3)$ $441 (33.9)$ N/AAnxious $89 (6.9)$ $605 (46.6)$ $204 (15.7)$ $401 (30.9)$ N/ALonely $91 (7.0)$ $713 (54.9)$ $154 (11.9)$ $341 (26.3)$ N/AWithdrawn $77 (5.9)$ $422 (32.5)$ $169 (13.0)$ $631 (48.6)$ N/AIn the past one week, how much has HSimpacted your sexual activity: $171 (13.2)$ $407 (31.3)$ $130 (10.0)$ $453 (34.9)$ $138 (10.6)$ Embarrassment $177 (13.6)$ $354 (27.3)$ $138 (10.6)$ $529 (40.7)$ $101 (7.8)$ Pain $187 (14.4)$ $437 (33.6)$ $144 (11.1)$ $427 (32.9)$ $104 (8.0)$ In the past one week, how much has your HSN/A $676 (52.0)$ $298 (22.9)$ $325 (25.0)$ N/Aimpacted your concentration (i.e., leisure, school or work):In the past one week, how much has your HSN/A $383 (29.5)$ $353 (27.2)$ $563 (43.3)$ N/A	Embarrassed	69 (5.3)	532 (41.0)	213 (16.4)	485 (37.3)	N/A
Anxious89 (6.9)605 (46.6)204 (15.7)401 (30.9)N/ALonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HSimpacted your sexual activity:Lack of desire171 (13.2)407 (31.3)130 (10.0)453 (34.9)138 (10.6)Embarrassment177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/Aimpacted your concentration (i.e., leisure, school or work):N/A383 (29.5)353 (27.2)563 (43.3)N/Aimpacted your life:141414141414	Irritable	55 (4.2)	578 (44.5)	225 (17.3)	441 (33.9)	N/A
Lonely91 (7.0)713 (54.9)154 (11.9)341 (26.3)N/AWithdrawn77 (5.9)422 (32.5)169 (13.0)631 (48.6)N/AIn the past one week, how much has HSimpacted your sexual activity:Lack of desire171 (13.2)407 (31.3)130 (10.0)453 (34.9)138 (10.6)Embarrassment177 (13.6)354 (27.3)138 (10.6)529 (40.7)101 (7.8)Pain187 (14.4)437 (33.6)144 (11.1)427 (32.9)104 (8.0)In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/Aimpacted your concentration (i.e., leisure, school or work):N/A383 (29.5)353 (27.2)563 (43.3)N/A	Anxious	89 (6.9)	605 (46.6)	204 (15.7)	401 (30.9)	N/A
Withdrawn       77 (5.9)       422 (32.5)       169 (13.0)       631 (48.6)       N/A         In the past one week, how much has HS impacted your sexual activity:       Lack of desire       171 (13.2)       407 (31.3)       130 (10.0)       453 (34.9)       138 (10.6)         Embarrassment       177 (13.6)       354 (27.3)       138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A         impacted your concentration (i.e., leisure, school or work):       In the past one week, how much has your HS       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A	Lonely	91 (7.0)	713 (54.9)	154 (11.9)	341 (26.3)	N/A
In the past one week, how much has HS         impacted your sexual activity:         Lack of desire       171 (13.2)       407 (31.3)       130 (10.0)       453 (34.9)       138 (10.6)         Embarrassment       177 (13.6)       354 (27.3)       138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A         impacted your concentration (i.e., leisure, school or work):       In the past one week, how much has your HS       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A         impacted your life:       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A	Withdrawn	77 (5.9)	422 (32.5)	169 (13.0)	631 (48.6)	N/A
impacted your sexual activity:       Lack of desire       171 (13.2)       407 (31.3)       130 (10.0)       453 (34.9)       138 (10.6)         Embarrassment       177 (13.6)       354 (27.3)       138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A         impacted your concentration (i.e., leisure, school or work):       In the past one week, how much has your HS       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A	In the past one week, how much has HS					
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Embarrassment       177 (13.6)       354 (27.3)       138 (10.6)       529 (40.7)       101 (7.8)         Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A         impacted your concentration (i.e., leisure, school or work):       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A         impacted your life:       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A	Lack of desire	171 (13.2)	407 (31.3)	130 (10.0)	453 (34.9)	138 (10.6)
Pain       187 (14.4)       437 (33.6)       144 (11.1)       427 (32.9)       104 (8.0)         In the past one week, how much has your HS       N/A       676 (52.0)       298 (22.9)       325 (25.0)       N/A         impacted your concentration (i.e., leisure, school or work):       In the past one week, how much has your HS       N/A       383 (29.5)       353 (27.2)       563 (43.3)       N/A         impacted your life:       104       1	Embarrassment	177 (13.6)	354 (27.3)	138 (10.6)	529 (40.7)	101 (7.8)
In the past one week, how much has your HSN/A676 (52.0)298 (22.9)325 (25.0)N/Aimpacted your concentration (i.e., leisure, school or work):N/A383 (29.5)353 (27.2)563 (43.3)N/Aimpacted your life:N/A383 (29.5)353 (27.2)563 (43.3)N/A	Pain	187 (14.4)	437 (33.6)	144 (11.1)	427 (32.9)	104 (8.0)
impacted your concentration (i.e., leisure, school or work): In the past one week, how much has your HS N/A 383 (29.5) 353 (27.2) 563 (43.3) N/A impacted your life:	In the past one week, how much has your HS	N/A	676 (52.0)	298 (22.9)	325 (25.0)	N/A
school or work): In the past one week, how much has your HS N/A 383 (29.5) 353 (27.2) 563 (43.3) N/A impacted your life:	impacted your concentration (i.e., leisure,					
In the past one week, how much has your HS N/A 383 (29.5) 353 (27.2) 563 (43.3) N/A impacted your life:	school or work):					
impacted your life:	In the past one week, how much has your HS	N/A	383 (29.5)	353 (27.2)	563 (43.3)	N/A
	impacted your life:					

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n = 1299(%)
470 (36.2)
465 (35.8)
456 (35.1)
405 (31.2)
194 (14.9)
157 (14.2)
146 (11.2)
132 (10.2)
117 (9.0)
103 (7.9)
74 (5.7)
72 (5.5)
55 (4.2)
47 (3.6)
47 (3.6)
46 (3.5)
33 (2.5)
25 (1.9)
12 (0.9)
10 (0.8)
9 (0.7)
7 (0.5)
232 (17.9)

 Table III: Frequency of Self-reported Comorbidities Among Global VOICE Participants

Percent of female patients (n=1,103)

Medical Treatment	n=1299 (%)
Antibiotic, oral	1,112 (85.6)
Intralesional corticosteroid	323 (24.9)
Biologic	270 (20.8)
adalimumab	208 (16.0)
infliximab	106 (8.2)
etanercept	25 (1.9)
secukinumab	15 (1.2)
ustekinumab	16 (1.2)
Anakinra	10 (0.8)
ixekizumab	5 (0.4)
Anti-Androgen	165 (12.7)
spironolactone	144 (11.1)
finasteride	26 (2.0)
Retinoid, oral	183 (14.1)
isotretinoin	150 (11.5)
acitretin	49 (3.8)
Immunosuppressive, traditional	113 (8.7)
methotrexate	88 (6.8)
cyclosporine	35 (2.7)
Mycophenolate mofetil	10 (0.8)
Systemic, miscellaneous	92 (7.1)
dapsone	60 (4.6)
zinc	24 (1.8)
oral contraceptive pill	11 (0.8)
cannabis	5 (0.4)
None	38 (2.9)
Procedural Treatment	1,075 (82.8)
incision and draining	909 (70.0)
excision	712 (54.8)
laser hair removal	136 (10.5)
deroofing	117 (9.0)
CO2 laser treatment	84 (6.5)
photodynamic therapy	13 (1.0)
None	224 (17.2)

 Table IV: Frequency of Current or Past Medical Treatments and Procedures Among Global

 VOICE Participants

\*Sum of counts for individual medications may exceed the overall count for that category if a patient reported use of multiple medications within a category.

Domain	Unmet Need	Me chanisms to Address Needs
Diagnosis	Disease awareness	•Promote advocacy and interdisciplinary education through patient support groups and
and Care		medical organizations; Research and peer-reviewed publication.
	Delay in diagnosis	•Develop a point of care diagnostic aid which facilitates distinction from abscess or inflamed
		epidermal cysts by non-dermatologists.
		•Promote the role of the dermatologists in diagnosis and management.
	Quality and cost of care	•Improve dermatology access to manage disease flares.
Symptoms	Control of symptoms	•Develop appropriate and effective management strategies to address pain, drainage, odor,
		fatigue and flare
Life Impact	Assessment of life impact	•Develop a disease-specific quality of life instrument to measure life impact
	Mental wellness	•Address psychosocial impact of the disease through interdisciplinary care with mental
		health professionals and advocates of well-being
Comorbid	Associated diseases	•Advance research to identify associated conditions, their related mechanisms, and their
Conditions		modification with treatment
		•Develop guidelines on evidence-based recommendations for prevention and screening of
		associated conditions
		•Establish interdisciplinary care teams to provide comprehensive care
Treatment	Safe and effective treatment	•Develop reliable and feasible tools to measure disease
		•Develop relevant outcome measures to assess efficacy of treatments
		•Advance research to identify disease mechanism and potential therapeutic targets
		•Develop medical treatments with improved efficacy and safety profiles
		•Evaluate outcomes for procedural treatments
		•Develop guidelines for pain management

Table V. Addressing Unmet Needs in Hidradenitis Suppurativa