

Insights on the Burden of Hidradenitis Suppurativa from a Patient Survey

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Learning Objective: Understand the disease burden of HS from a patient perspective

Take Away Messages:

- Respondents indicated a high disease burden from the symptoms and psychological impact of HS
- There remains a high unmet need for safe, effective treatments to reduce the burden of disease felt by patients

Disclosures: C. Zouboulis: Honoraria as an advisor and speaker for studies or lectures associated with HS, but not with the current study, from AbbVie, Idorsia, Incyte, InflaRx, Janssen, Novartis, Regeneron and UCB Pharma. His department has received grants from AbbVie, InflaRx, Novartis and UCB Pharma for his participation as an investigator; I. Hamzavi: Consultant for Incyte, Clarify Medical and Pfizer (fees paid to institution); Consultant for Boehringer Ingelheim, Janssen and UCB (fees paid to self); Principal Investigator for Pfizer, Bayer, Lenicura and Incyte (fees paid to institution), and sub-investigator for Chemocentyx; Served on Advisory Board for AbbVie (no compensation received) and as president of the HS Foundation (non-compensated role); H. Lapidus Glassner: Employee of MyHealthTeams, who received funding from UCB Pharma to conduct this survey; I. Pansar: Employee of UCB Pharma; H. Lev-Tov: No relevant conflicts to declare.

Plain Language Summary

Why was this study needed?

There is very little information available on how HS affects patients' daily lives, told from the point of view of the patients themselves

What did this study show?

Of the patients who participated in the survey:

- 6/10 said that the **painful**, swollen, boils lumps and abscesses were the symptom that affected their lives most
- 7/10 said that they suffered from either **anxiety** or **depression**
- 9/10 were **uncomfortable** with the idea of **intimacy**, and nearly 9/10 said that the **disease affected the clothing** that they chose to wear

Why is this important?

This study shows that having HS has a large impact on patients' day-to-day lives, and highlights that better treatments are needed so that they can enjoy a better quality of life

Background & Objective

- Patients with hidradenitis suppurativa (HS) endure painful, inflammatory nodules and abscesses, which can rupture and form draining abscesses and draining tunnels
- Extensive scarring and fibrosis in sensitive locations can lead to contractures and limb mobility limitations
- The pain and malodorous discharge can have a substantial effect on patients' quality of life
- Despite this, real-world, **patient-reported** data on the disease burden of HS are lacking

We aimed to assess the social, psychological and physical disease burden of HS using a patient questionnaire

Survey Methodology



Online survey (November 5 – December 20 2020)

- Questions on demographics, treatment, and experience of HS: symptoms, impact on daily life, burden of disease



Recruitment via:

- Emails to members of myHSteam
- Posts on myHSteam Facebook page, Google ads and Quora ads



240 respondents completed the survey:

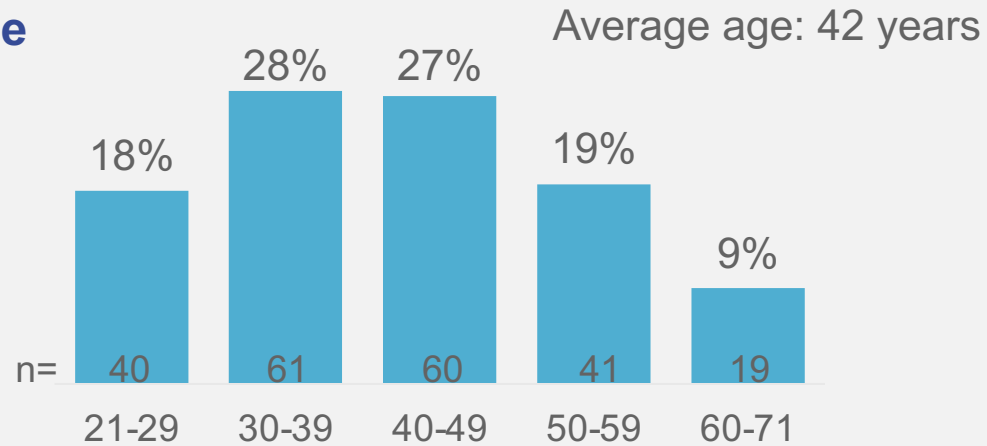
- ≥ 21 years of age, with a confirmed/suspected diagnosis of HS
- 67% recruited from myHSteam (primarily via email invitations) (n=164)
- 33% recruited from Google AdWords (n=65), Facebook (n=5), and Quora (n=6)



Only results from female participants (n=221, 92%) are shown

Respondent Characteristics (Female population)

Age



Country



4% South Africa; 3% Australia; 2% Ireland; 1% Netherlands;
1% New Zealand; 5% Other

Race/Ethnicity

United States:^a

- 69% White/Caucasian (n=74)
- 25% Black/African-American (n=27)
- 8% Latina/Hispanic (n=9)

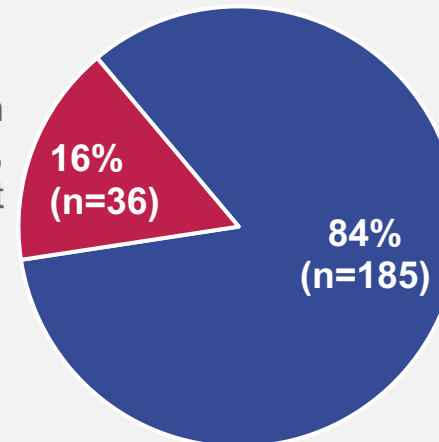
United Kingdom:

- 90% White British (n=47)

All other groups^b ≤3%

Diagnosis

No, I have not been diagnosed yet, but I think I have it

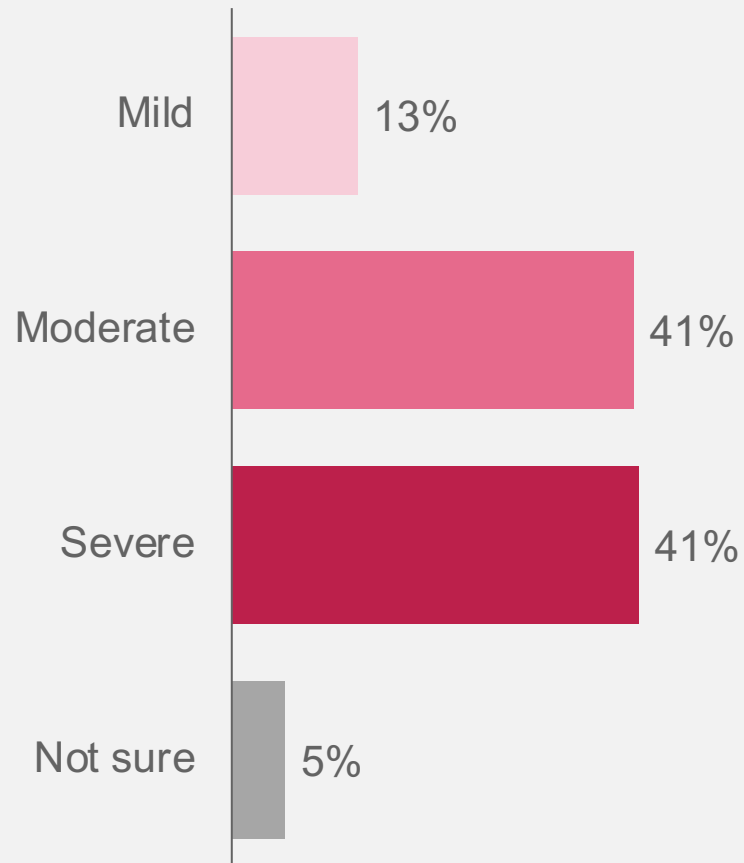


Yes, a doctor has diagnosed me

^aIn the US the question was a multiple response, and so sums to >100%; ^bOther groups consisted of US: 1% Asian, 3% Other; UK: 2% Mixed/multiple, 2% Black/Black British/Caribbean/African, 2% Asian/Asian British, 2% Other, 2% Prefer not to say.
Female population; n=221.

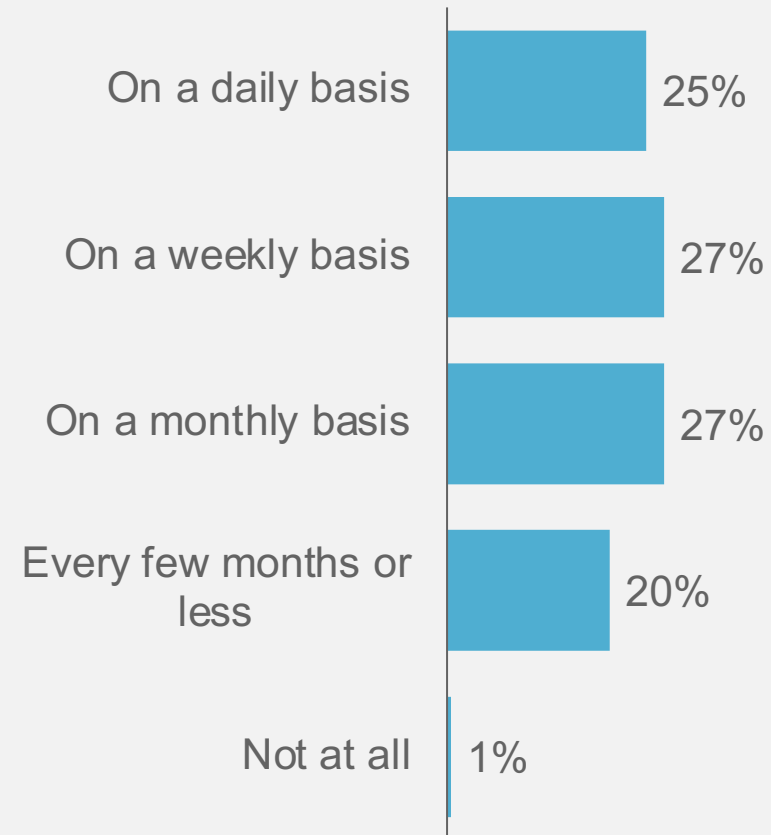
Respondent Characteristics (Female Population)

Self-Identified Stage of HS



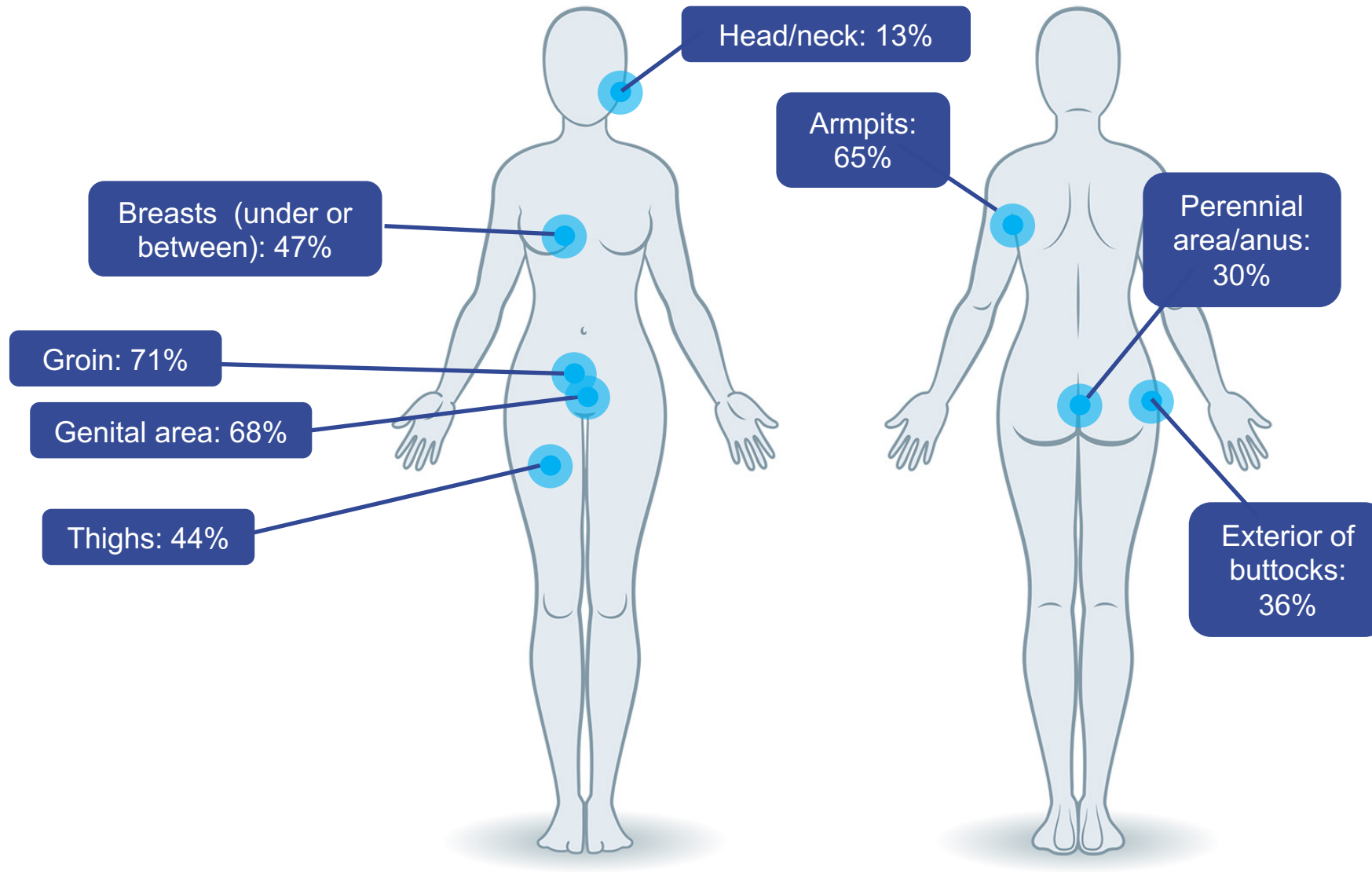
Q4. Overall, would you describe your HS as mild, moderate or severe?
Note: severity was self-reported and not physician-assessed.
Female population; n=221.

Frequency of Self-Identified Flare Ups



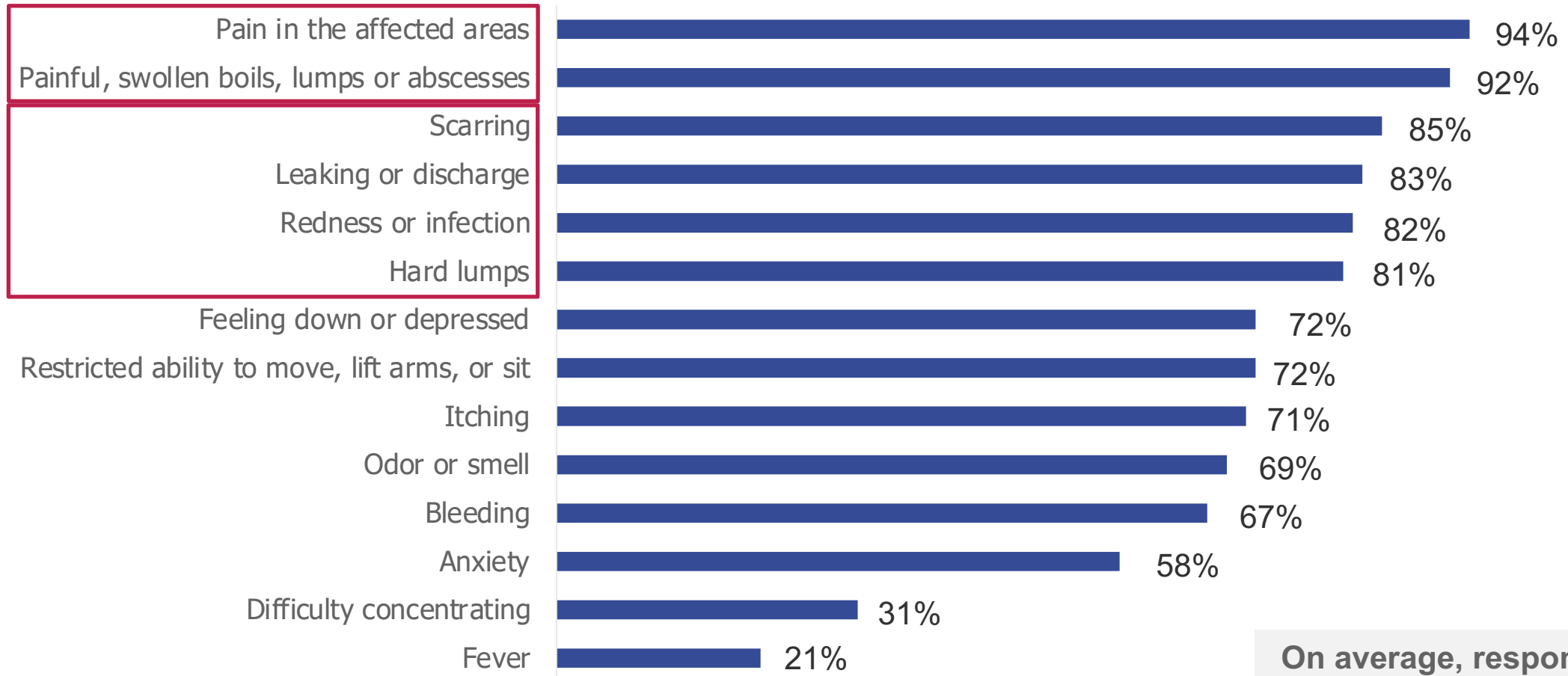
Q5. How often have you experienced periods of increased HS symptoms (or flare-ups) in the past 12 months?
Note: flares were self-reported and not physician-assessed. Female population; n=221.

Where on the Body HS is Experienced



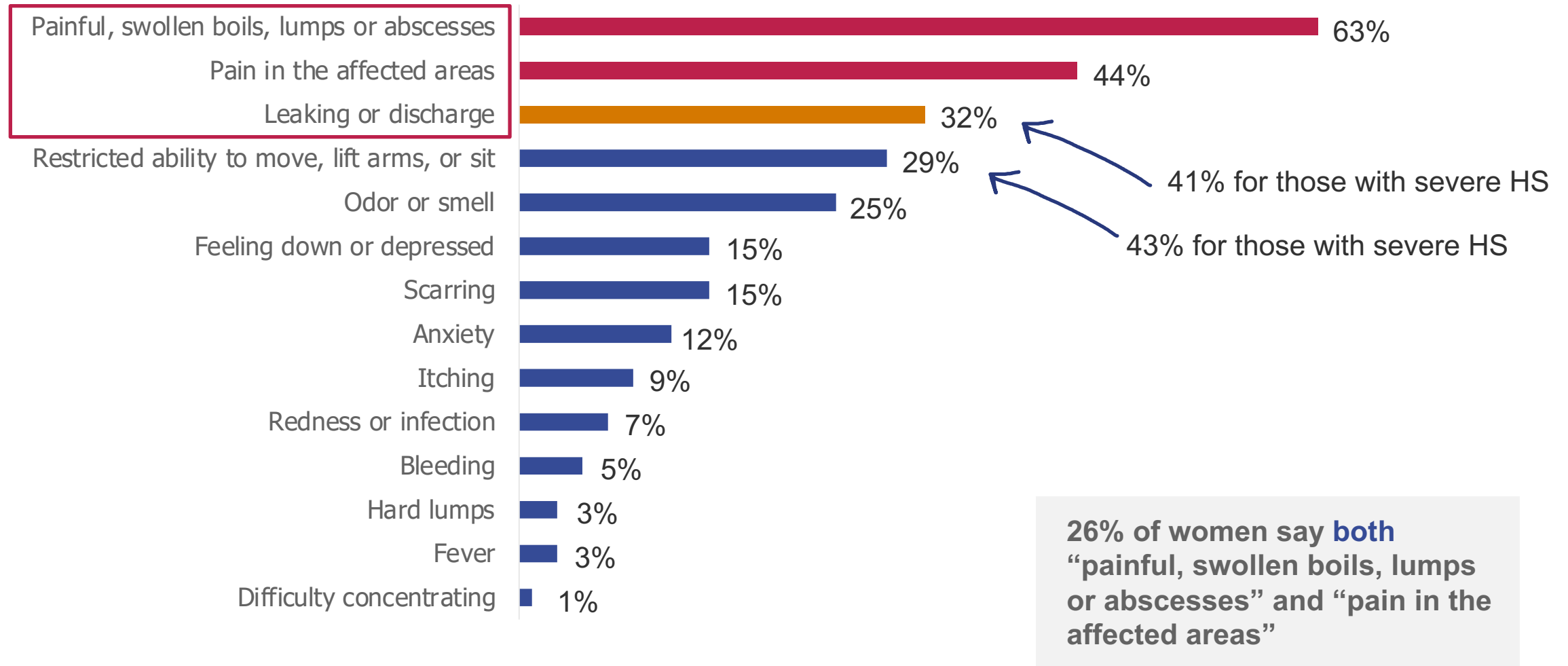
Q6. Where on your body do you experience HS? Please select all that apply.
Female population; n=221.

Symptoms of HS Experienced



On average, respondents experienced **9–10** different symptoms

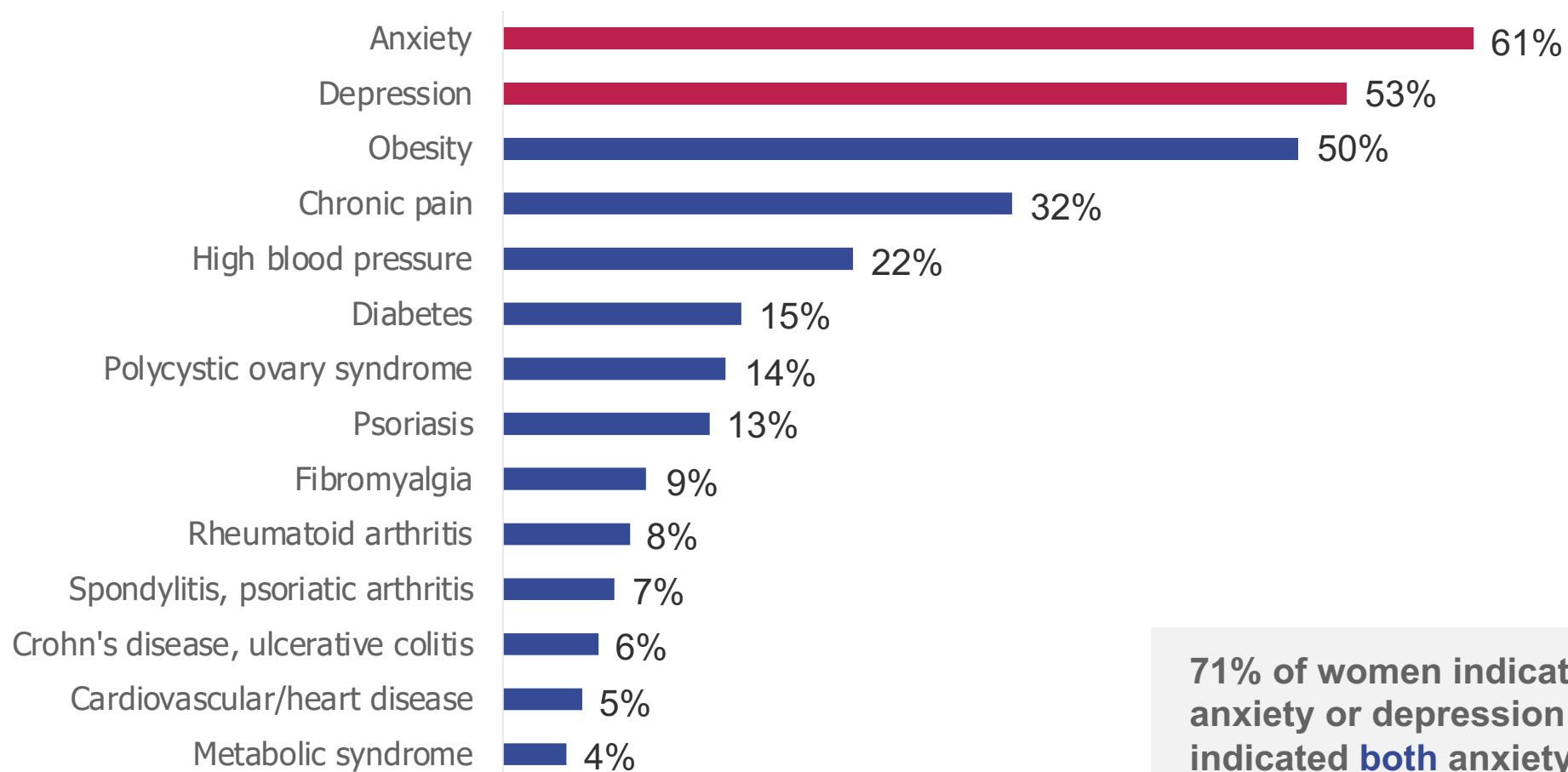
Symptoms with the Greatest Impact on Daily Life



Q8. Which symptoms have the greatest impact on your daily life? Please choose no more than three symptoms. Note: question was multiple response, so the total sums to more than 100%.

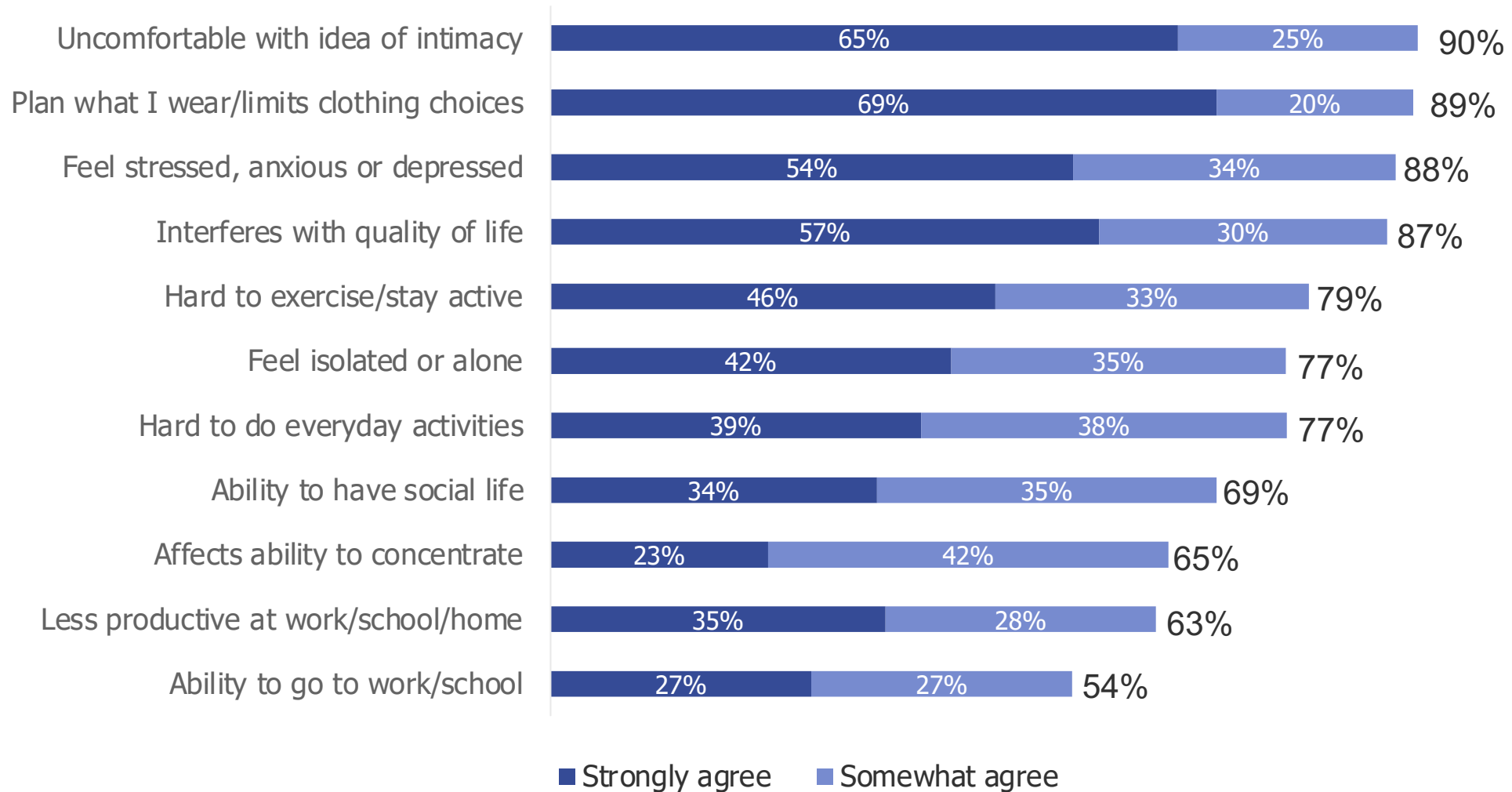
Female population; n=221, or n=91 for the severe HS group. Note that severity was self-identified.

Commonly Reported Health Conditions



71% of women indicate either anxiety or depression; 43% indicated **both** anxiety and depression

Impact of HS on Aspects of Daily Life



Q26. Please help us understand the impact living with HS has had on your life. How much do you agree or disagree with each of the following statements?
 Female population; n=221.

Conclusions



Targeting individuals who participate in a community **for HS** resulted in **higher survey participation** rates than individuals recruited **from general web sources**



The 221 female respondents experienced **high disease burden** from the symptoms and psychological impact of HS



There remains a **high unmet need** for safe, effective treatments to reduce the burden of disease felt by patients