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1 **Secondary care management of patients with hidradenitis suppurativa in the United**
2 **Kingdom and Ireland: a survey of current practice**

3
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3

4

5 **What is already known about this topic?**

6 • There are only a limited number of hidradenitis suppurativa (HS) specialist services
7 across the UK and Ireland, although that number is growing.

8 • HS is a multimorbid disease requiring a multidisciplinary team approach to its
9 management.

10 • There is a lack of robust evidence to support the use of traditional non-targeted therapy in
11 the management of HS.

12 **What does this study add?**

13 • Disparity exists between treatment availability within HS-specialist and non-specialist
14 settings.

15 • Improved availability of deroofing training is needed to address unequal access to
16 surgery.

17 • Clinicians lack confidence in current treatment effectiveness for HS, emphasising a need
18 for new targeted therapies to improve patient outcomes.

19 • Access to HS-specific multidisciplinary team (MDT) meetings is limited. The HS UK
20 and Ireland Network (H-SKIN) aims to improve this by establishing a national MDT.

21

1 **Abstract**

2 Background. Despite therapeutic advances for hidradenitis suppurativa (HS), specialist
3 multidisciplinary services remain limited. The UK and Ireland HS Network (H-SKIN) seeks to
4 advance evidence-based management and optimise outcomes through collaborative clinical
5 practice.

6 Objectives. This study examined variations in management and access to treatment between
7 specialist and non-specialist services.

8 Methods. An online survey open from April to August 2025 explored clinical practice in HS
9 management. It was distributed via H-SKIN, the British Association of Dermatologists (BAD)
10 and the British Dermatology Nursing Group (BDNG) networks.

11 Results. The survey received 99 responses (38 H-SKIN; 61 BAD/BDNG). Medication use
12 varied, with the biggest differences in metformin (89% H-SKIN; 62% BAD/BDNG),
13 secukinumab (92% H-SKIN; 52% BAD/BDNG) and spironolactone (71% H-SKIN; 46%
14 BAD/BDNG). Deroofing and wide local excision were available to 42% and 84% respectively,
15 of the H-SKIN group compared to 23% and 70% in the BAD/BDNG group.

16 Pain scores were recorded more often in the H-SKIN group (61% versus 32%). Mental health
17 screening was conducted by 89% of the H-SKIN group and 69% of the BAD/BDNG group.
18 Psychological support was available to 37% of the H-SKIN group compared to 8% of the
19 BAD/BDNG group. In the BAD/BDNG group 79% had no access to a Multidisciplinary Team
20 (MDT) to discuss HS patients.

21 Conclusion. The results highlight UK disparities in access to HS medical therapies, deroofing
22 and MDT support. Improvements in the standardisation of care are needed. The new National
23 HS MDT run by H-SKIN will help to facilitate this by improving access to specialist support.

1 **Introduction**

2 Hidradenitis suppurativa (HS) is a chronic, painful skin disease that causes abscesses, nodules,
3 tunnels and scarring in the skin folds. A recent global meta-analysis reported a prevalence of
4 0.99%. In Europe, it disproportionately affects women at a ratio of 3:1¹⁻³. Disease flares are
5 common, and the high disease burden impacts patients' quality of life⁴. HS is associated with
6 multiple comorbidities, including cardiovascular disease and depression². The complexity of
7 HS means that a multidisciplinary team (MDT) approach is needed⁵. This is best provided in a
8 secondary care specialist service, but these services remain uncommon⁶.

9 The therapeutic landscape for HS is rapidly evolving, with 25 commercial clinical trials listed as
10 recruiting on www.clinicaltrials.gov. Many traditional treatments for HS lack a strong evidence
11 base to support their use. The British Association of Dermatologists (BAD) guidelines for
12 managing HS were published in 2018⁷, with an update currently in progress.

13 Specialised commissioning for HS in the UK focuses biologic care on a small number of centres.
14 Other centres seeking access to biologics for HS rely on face-to-face or virtual multidisciplinary
15 team (MDT) consultations provided by the specialist centre. This can lead to considerable delays
16 in patient care. The HS United Kingdom (UK) and Ireland Network (H-SKIN) was established
17 in 2023 to bring together clinicians working in specialist services to improve the care of patients
18 with HS across the UK and Ireland.

19 The present study aimed to investigate potential heterogeneity in HS care across different
20 settings and to quantify the uptake of evidence-based HS management, where evidence is
21 available to guide care.

22

23 **Methods**

24 An online survey was created using Jisc Online Surveys (<https://app.onlinesurveys.jisc.ac.uk>),
25 piloted, and then distributed to H-SKIN members. A separate survey link, to distinguish between
26 the two groups, was shared via the BAD and British Dermatological Nursing Group (BDNG)
27 mailing lists and during members' events. Both groups received several reminder emails. The
28 survey was open from 25 April 2025 to 15 August 2025.

29 Participants were invited to complete an anonymous 63-question survey (appendix S1). The
30 survey explored respondents' clinical environments, MDT collaboration, and HS patient support
31 services. Additional questions examined current comorbidity screening, prescribing, and surgical
32 procedures for patients with HS. To encourage completion, not all questions were mandatory.

33

34 **Results**

35 The H-SKIN group had 38 responses from its 59 members (response rate 64.4%). The BAD and
36 BDNG group received 61 responses from a combined membership of 5275 members, of whom
37 204 clicked on the link (response rate 29.9%). Demographics of respondents are shown in Table
38 1.

1 *Multidisciplinary team*

2 In the H-SKIN group, 63% saw patients in a dedicated HS specialist clinic compared to 17% in
3 the BAD/BDNG group. In the H-SKIN group, 34% had a dedicated HS multidisciplinary team
4 (MDT) meeting, and 21% discussed their HS patients within a general biologics MDT. In the
5 BAD/BDNG group, 6% had a dedicated HS MDT, and 14% were discussed in a general
6 biologics MDT, leaving 79% with no MDT support. The most common additional members of
7 the MDT are shown in Table 2.

8 *Non-targeted medical therapy*

9 Respondents were asked about their current prescribing practices and their perceptions of
10 treatment effectiveness (Table 3). Only one respondent across both groups used spironolactone in
11 male patients. The H-SKIN group was more likely to use it specifically for female patients with
12 flares linked to their menstrual cycle (44% vs. 24%). In the BAD/BDNG group, 15.9% of
13 patients were prescribed Dapsone and 17.2% acitretin, compared to 16.6% and 16.7%
14 respectively, in the H-SKIN group.

15 For metformin, 74% of the H-SKIN group use the modified-release formulation compared to
16 53% in the BAD/BDNG group. In both groups, metformin was primarily used as an adjunct to
17 other therapies, regardless of disease severity or comorbidities. Across both groups, 23% of
18 patients prescribed metformin discontinued it due to adverse effects, including gastrointestinal
19 symptoms.

20 Glucagon-like peptide-1 (GLP-1) agonists were unavailable to any H-SKIN members, and only
21 4(6%) of the BDNG/BAD group. Of those, two worked outside England (Ireland and Northern
22 Ireland) and one worked solely in private practice. In the H-SKIN group, 84% said they would
23 prescribe these medications to their patients if permitted, compared to 49% in the BAD/BDNG
24 group.

25 *Surgical treatment*

26 Deroofing was available to 42% of the H-SKIN group compared to 22% of the BAD/BDNG
27 group (Table 4), with 53.3% of procedures performed by a dermatologist. In sites where a
28 dermatologist did not perform the procedure, the operator was most commonly a plastic surgeon.
29 Patients referred for a wide local excision for their HS typically waited several months (40.5%),
30 16.2% waited over a year, and 5.4% often never received the procedure because HS patients
31 were regarded as low priority.

32 *Biologic therapy*

33 In the H-SKIN group 95% could prescribe adalimumab compared to 57% in the BAD/BDNG
34 group. Of those who could not prescribe, 29% discussed cases at a virtual MDT with a specialist
35 centre, and 71% had to refer to a specialist centre. Adalimumab levels were monitored by 47%
36 of H-SKIN respondents, compared to 10% in the BAD/BDNG group. Among those who checked
37 levels, 24% increased the dose if the level was less than 5, 35% increased the dose if the level
38 was less than 10, and 29% switched therapy if the level was less than 5. Antibodies were checked
39 in 66% of H-SKIN respondents, versus 27% in the BAD/BDNG group, with 53% switching
40 therapy and 13% adding a systemic agent to reduce antibody production if present.

1 Secukinumab was prescribed by 92% of the H-SKIN group compared to 52% of the
2 BAD/BDNG group. Respondents in both groups were asked to agree with the statement
3 'Secukinumab is an effective second-line treatment (after adalimumab) for hidradenitis
4 suppurativa (0-disagree, 10-strongly agree)'. The H-SKIN group rated the statement with a mean
5 of 5.81, compared to 6.30 in the BAD/BDNG group.

6 In the H-SKIN group, 66% prescribed infliximab, compared to 43% in the BAD/BDNG group,
7 with 76% needing to use the exceptional funding route to obtain this. Involvement in clinical
8 trials varies across both groups, with 55% of the H-SKIN group, compared to 10% of the
9 BAD/BDNG group, recruiting to trials.

10 *Flare Management*

11 In the H-SKIN group, 87% prescribed rescue therapy for acute flares compared to 76% in the
12 BAD/BDNG group. The most common flare management involved a two-week supply of
13 antibiotics (63.3%), with other options including both shorter and longer courses of antibiotics
14 and oral prednisolone, either alone or combined with antibiotics.

15 *Psychological support*

16 Differences in access to psychological therapy were noted, with 37% having access in the H-
17 SKIN group compared to 8% in the BAD/BDNG group. Of those with access, 37% had
18 psychological support embedded in HS clinics, 37% had a defined referral pathway for severe
19 mental health problems, and 26% had access as part of lifestyle support.

20 *Screening, disease severity tools and investigations*

21 The largest differences in the use of screening and disease severity tools (Figure 1) were seen in
22 recording of a pain score (61% H-SKIN; 32% BAD/BDNG) and use of the International HS
23 Severity Score System (IHS4) (58% H-SKIN; 15% BAD/BDNG). Screening for mental health
24 problems was done by 89% of the H-SKIN group compared to 69% in the BAD/BDNG group.
25 Severity measures for depression and anxiety were used by 45% and 39% respectively, in the H-
26 SKIN group and 27% and 28% respectively, in the BAD/BDNG group.

27 When requesting investigations (Figure 2), the H-SKIN group were more likely to request
28 Magnetic Resonance Imaging (MRI) for extensive groin/perineal/perianal disease (55% H-
29 SKIN; 20% BAD/BDNG).

30 Considering screening for lifestyle factors and comorbidities (Figure 3), the greatest differences
31 were seen in screening for sexual dysfunction (39% H-SKIN; 18% BAD/BDNG) and
32 spondyloarthritis (58% H-SKIN; 21% BAD/BDNG).

33 *Free comments section*

34 The most common theme in the free text was frustration with being unable to prescribe biologic
35 medication for clinicians working outside a specialist-commissioned service. Many reported long
36 waits for patients to be seen by these specialist services, leading to delays in accessing biologic
37 therapy, resulting in disease progression. Other concerns were a lack of provision for surgery,
38 weight management and psychological services and difficulty in managing HS within the time
39 constraints of a general dermatology clinic due to the multiple facets of the disease and
40 associated comorbidities. Finally, concern was raised regarding access to newer therapies in light

1 of bimekizumab being withdrawn by the manufacturer from the UK National Institute for
2 Clinical Excellence (NICE) Single Technology Appraisal for HS.

4 **Discussion**

5 The results of this survey provide insight into the current management of HS in the UK and
6 Ireland. The findings highlight ongoing disparities in treatment provision between specialist and
7 non-specialist services, particularly regarding MDT support, surgical interventions, and access to
8 biologics.

9 A relative lack of global data on HS clinical practice exists, hindering meaningful comparisons.
10 Comparisons can be made, however, with previous UK surveys and a 2021 BAD national audit
11 of HS management⁸. The first survey on the secondary care management of HS in the UK was
12 conducted in 2015⁹ and was repeated following the introduction of the BAD guidelines in
13 2019¹⁰. In the 2019 survey, respondents were asked to identify their top 10 interventions.

14 Acitretin was chosen by 65%, and dapsone by 63%, ranking them third and fourth respectively,
15 after rifampicin and clindamycin, and adalimumab¹⁰. In our survey, 88% and 70% respectively,
16 prescribed the medications. However, usage has decreased, with less than 20% of patients being
17 prescribed either drug. The result is consistent with perceived efficacy for acitretin and dapsone
18 being the lowest of all the medications surveyed across both groups (Table 3). These low usage
19 rates reflect the general shift to targeted biologic therapies since publication of the 2018 BAD
20 guidance in which they feature as second line treatments after antibiotics and before biologics¹¹.
21 The reduction in UK usage of acitretin and dapsone aligns with the new 2025 European
22 guidance, in which they have moved to third-line treatment options¹².

23 Metformin and spironolactone use has increased from 52% and 28% respectively in 2019 to 73%
24 and 57%. This is likely secondary to the growing number of reviews supporting their use, the
25 increasing recognition of the importance of hormonal therapies in the treatment of HS and
26 awareness of increased risks of diabetes and cardiovascular disease¹. Despite this, there is no
27 randomised controlled trial to support the use of either drug, and only one retrospective case
28 series of 53 patients reporting 68% subjective improvement with metformin use^{12,13}. Challenges
29 also remain in encouraging primary care to take over prescribing spironolactone and metformin,
30 with 30.9% overall reporting that primary care declined to prescribe these medications for HS.

31 The use of GLP-1 agonists in dermatology is rapidly evolving. Our survey showed that if
32 available, both groups would consider prescribing GLP-1 agonists for patients with HS. Beyond
33 their role in weight loss, they have anti-inflammatory properties and down-regulate
34 proinflammatory responses¹⁴. A recent systematic review of GLP-1 agonists in HS demonstrated
35 a statistically significant reduction in active nodule count in 58.6% of patients¹⁵. In the UK, their
36 use is restricted to those with a body mass index (BMI) of at least 35kg/m² and at least one
37 weight-related condition or in those with a BMI of 30-35kg/m² under the care of a weight
38 management service. Despite the known association with obesity, HS is not listed as a weight-
39 related condition by NICE¹⁶. Many patients with HS are privately funding the medication. It is

1 postulated that those reporting access to GLP-1 agonists in our survey are either working outside
2 the National Health Service or referencing patients who are privately funding the medication.
3 Previous survey data showed that between 2014 and 2019, there was a modest improvement in
4 the uptake of surgical procedures. This was apparent in both wide local excisions (35% in 2014;
5 43% in 2019) and deroofing (28% in 2014; 33% in 2019). Our study shows that this pattern has
6 continued in the H-SKIN group, with 84% having access to wide local excision and 42% to
7 deroofing. Although access to wide local excision has improved for the BAD/BDNG group
8 (68%), access to deroofing remains limited (22%).

9 The 2019 survey showed variation in flare management, with intravenous antibiotics (32%) and
10 incision and drainage (30%) being the most common approaches. Our results indicate that a lack
11 of consensus on flare treatments persists, but clinicians are now more likely to prescribe a two-
12 week course of oral antibiotics (63.6%). No respondents in either group suggested incision and
13 drainage as a flare management option in the free-text response. The European guidelines¹²
14 include flare management in many of the treatment sections, but a dedicated section on flare
15 management is absent, a gap that future HS guidelines could address.

16 HS has a known association with mental health problems and suicidality^{17,18}. The 2021 BAD
17 National audit found that 40% of respondents screened for depression and 25% screened for
18 anxiety⁸, whereas in our survey, 89% of H-SKIN and 69% of the BAD/BDNG group screened
19 for mental health problems, showing a marked increase. Despite this, less than 50% of both
20 groups assessed for suicidality. A barrier to suicidality assessment may be the lack of provision
21 of psychological support for patients, with only 19% of all respondents having psychological
22 support available, and only 7% having disease-specific support. By improving access to disease-
23 specific psychological support for patients, patient outcomes could be improved¹⁹.

24 Limitations of the survey include the low response rate in the BAD/BDNG group. Non-response
25 or sampling bias is possible because those interested in HS are more likely to have completed the
26 survey compared to those who occasionally see patients with HS and have limited access to
27 specialist services. Hence, our survey may have underestimated differences between the H-SKIN
28 and BAD/BDNG responder groups. Regarding limitations of the survey design, response bias is
29 possible where multiple options were given, such as in the comorbidity and screening questions.
30 To better capture nuances in responses, a mix of open and closed questions was used. To explore
31 this further, qualitative interviews could be considered as part of a future project. Additionally, a
32 further national audit of HS management would help validate the survey findings.

33 While Hurley staging remained the most widely used disease assessment tool, it is designed for
34 surgical purposes and describes severity with an emphasis on scarring at a single affected body
35 site. It does not consider the extent of the disease and the overall inflammatory burden and may
36 be inadvertently used as a global severity assessment tool^{20,21}. The refined Hurley classification
37 provides more global insight by considering the number of skin tunnels, number of affected body
38 sites and degree of inflammation²². Uptake of the HS Quality Of Life (HiSQOL) instrument²⁰
39 was twice as high in the H-SKIN group compared to the BAD/BDNG, reflecting HiSQOL being

1 a HS-specific instrument, compared to the Dermatology Life Quality Index (DLQI) instrument
2 used in many other skin conditions.

3 The least commonly assessed impacts arising from HS across both groups were sexual
4 dysfunction and fatigue. Both symptoms are well documented in HS, but patients are reluctant to
5 mention unless directly asked^{23,24}. Impact on sexual health is assessed by two questions in
6 HiSQOL, while the Hidradenitis Suppurativa Core Outcomes Set International Collaboration
7 (HiSTORIC)²⁵ is finalising an HS-specific fatigue instrument.

8 Patients report that the most problematic symptom in HS is the associated pain²⁵. The assessment
9 of a pain score in patients remained low, and only two respondents had chronic pain services
10 attend their MDT. The European guidelines highlight the need to measure pain, particularly as a
11 marker of treatment response¹². A recent study suggested that asking patients to report their worst
12 or average pain over 7 days via a numerical rating scale from 0-10 is an effective instrument to
13 measure pain magnitude²⁶.

14 There is a disparity in access to adalimumab for HS because HS falls under Specialised
15 Commissioning, in contrast to chronic plaque psoriasis, for which all UK secondary care
16 dermatology centres can prescribe biologics. HS was listed within Specialised Commissioning
17 because, at the time, it was considered a relatively rare disease, making specialist centres the
18 preferred approach to manage small patient numbers requiring specialised care. The decision has
19 not been reversed yet despite HS prevalence estimates increasing tenfold, from 0.1% to
20 0.99%^{3,27}. The National Specialised Dermatology Clinical Reference Group is currently working
21 to address this issue.

22 The mean perceived efficacy in the H-SKIN group of all non-targeted medications was 4.9/10.
23 With secukinumab, the second-line biologic therapy licensed for HS, the perceived efficacy was
24 5.8/10. The expectations of patients with HS and clinicians are increasing. New drug trials now
25 report Hidradenitis Suppurativa Clinical Response (HiSCR) 75 and 90 data compared to HiSCR
26 50. There remains a need for ongoing research into new targeted therapies for HS.

27 Deroofing is a straightforward procedure that can be performed by a dermatologist and
28 demonstrates high rates of disease improvement and patient satisfaction²⁸. This study emphasised
29 the need for deroofing training to improve access for patients regardless of their geographical
30 location within the UK and Ireland. For those requiring wide local excision, the current survey
31 demonstrates that patients may have to wait years for their procedures, as HS is often considered
32 a low priority. Hence, earlier intervention with more effective medical therapies is required to
33 prevent the extent of scarring exceeding the limits of deroofing under local anaesthetic.

34 The gold standard for managing any chronic disease with multiple comorbidities is a
35 multidisciplinary approach²⁹. Despite this, even within the H-SKIN group, there was limited
36 access to a dedicated MDT. Both groups were asked whether a national MDT for HS would be
37 beneficial, and there was support from over 95% of respondents in both groups. H-SKIN
38 launched the first online national MDT for HS in September 2025 to improve access to specialist
39 advice for all patients, regardless of geographical location or clinical setting.

1 **Conclusion**

2 Overall, these findings emphasise the need for improved access to targeted medical therapies and
3 deroofting, and greater standardisation of care for HS. It is important to address disparities in care
4 to ensure all patients have access to comprehensive support for this complex disease regardless
5 of geography. One practical approach is a hub-and-spoke model, with specialist centres across
6 the UK and Ireland offering advice and support to less experienced centres. The new national HS
7 MDT will help to support this model and promote collaborative working.

8 **Figure Legends**

10 Figure 1: Percentage of respondents using disease severity or screening instruments

11 Figure 2: Percentage of respondents using screening investigations

12 Figure 3: Percentage of respondents screening for comorbidities

13

14

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		H-SKIN n (%) (n=38)	BAD/BDNG n (%) (n=61)	
Role	Consultant	29 (78)	44 (72)	
	Resident/ Fellow	0	6 (10)	
	Staff Associate	2 (5)	2 (3)	
	Specialist/Associate Specialist			
	Specialist Nurse/Advanced practitioner	6 (17)	9 (15)	
Geography	Wales	1 (3)	2 (3)	
	Scotland	8 (21)	7 (11)	
	Northern Ireland	2 (5)	5 (8)	
	Ireland	0	2 (3)	
	South West	5 (13)	5 (8)	
	North East	3 (8)	4 (7)	
	North West	2 (5)	8 (13)	
	Yorkshire and the Humber	0	4 (7)	
	East Midlands	0	6 (10)	
	West Midlands	2 (5)	6 (10)	
	East of England	1 (3)	5 (8)	
	London	13 (34)	6 (10)	
	South East	1 (3)	1 (2)	
	Hospital Setting	District General	5 (13)	17 (28)
		Teaching Hospital	33 (87)	42 (69)
Community Clinic		0	1 (2)	
Private Sector		0	1 (2)	
Number of HS patients seen each month	None	0	5 (8)	
	1-5	7 (18)	30 (49)	
	6-10	8 (21)	18 (30)	
	11-20	13 (34)	5 (8)	
	21-30	6 (16)	1 (2)	
	30+	4 (11)	1 (2)	
Dedicated HS service	Yes	24 (63)	11 (18)	
Dedicated HS MDT	Yes	13 (34)	4 (6)	

1
2 Table 1: Demographics of survey respondents
3

MDT Members	Speciality available n (%) (n=28)
Surgeon for general anaesthetic procedures	17 (61)
Microbiologist/ infectious disease physician	9 (32)
Gastroenterologist/ colorectal surgeon	8 (29)
Psychologist	7(25)
Formal wound healing service	3 (11)
Chronic pain input	2 (7)
Urologist	2 (7)
Rheumatologist	1 (4)
Gynaecologist	1 (4)
Weight management service	1 (4)

1 Table 2: Specialities that are part of an MDT service (described as a named individual who
2 does not have to be physically present in the clinic)

3

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Medication	H-SKIN (n=38)		BAD/BDNG (n=61)	
	Used n (%)	Perceived efficacy	Used n (%)	Perceived efficacy
Metformin	34 (89)	5.1	38 (62)	5.6
Spironolactone	27 (71)	5.1	29 (46)	4.9
Dapsone	25 (66)	4.2	44 (70)	4.4
Acitretin	30 (81)	4.5	48 (77)	4.5
GLP-1 Agonists	0	5.2	4 (6)	8.3
Intralesional steroids	22 (58)	5.3	30 (48)	5.1

1 Table 3: Non-targeted medical therapy usage and their perceived efficacy (efficacy
2 measured on a scale of 0-10, X is an effective treatment, 0-disagree, 10 strongly agree)

3

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	H-SKIN n (%) (n=38)	BAD/BDNG n (%) (n=61)
Deroofing	16 (42)	14 (23)
Laser/light hair removal	8 (21)	10 (16)
Surgeon available for procedures requiring general anaesthetic	32 (84)	43 (70)

1 Table 4: Availability of surgery for HS

2

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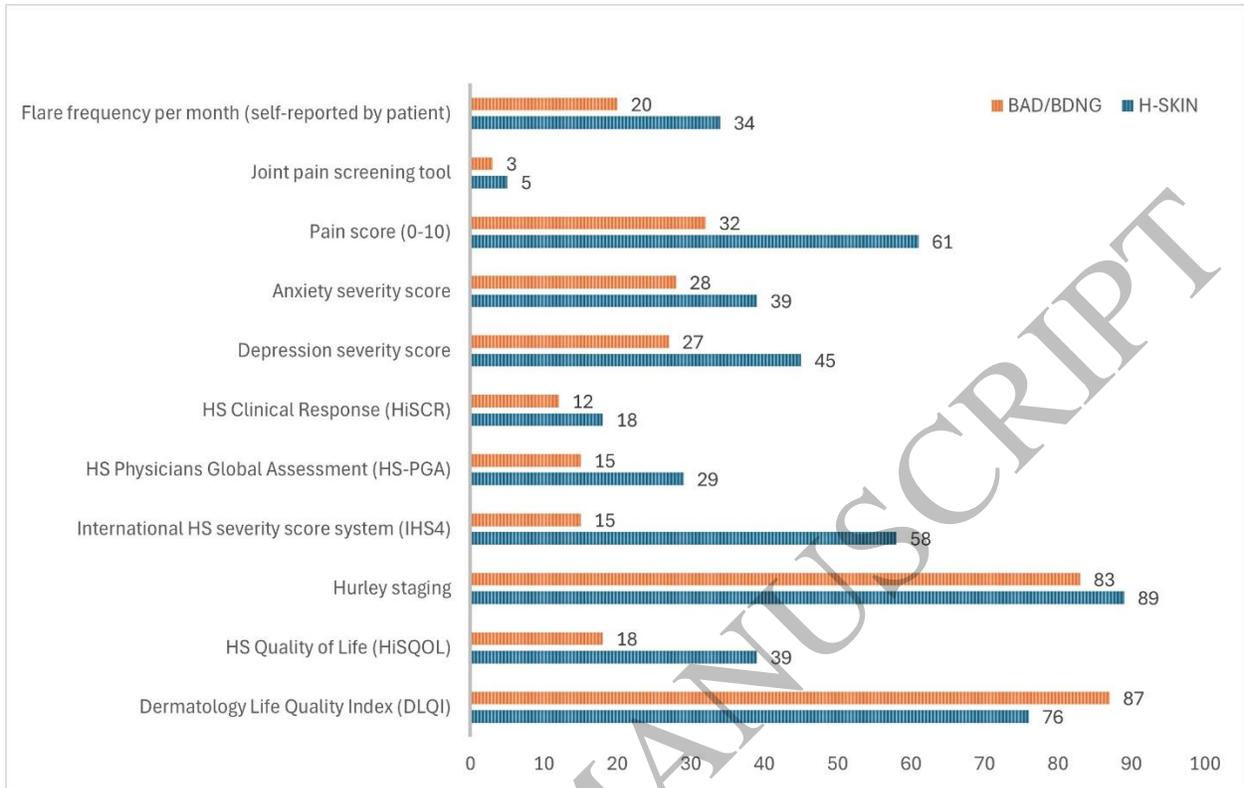


Figure 1
165x105 mm (x DPI)

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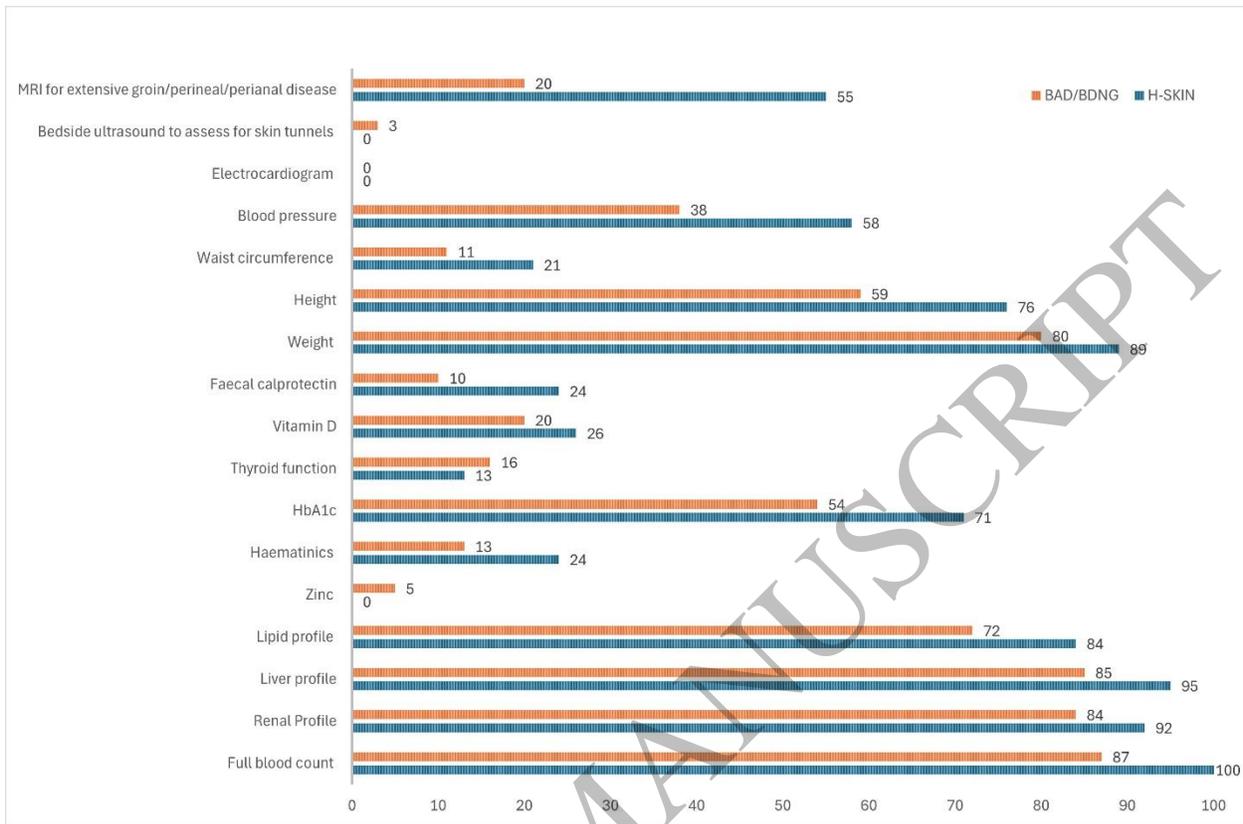


Figure 2
165x109 mm (x DPI)

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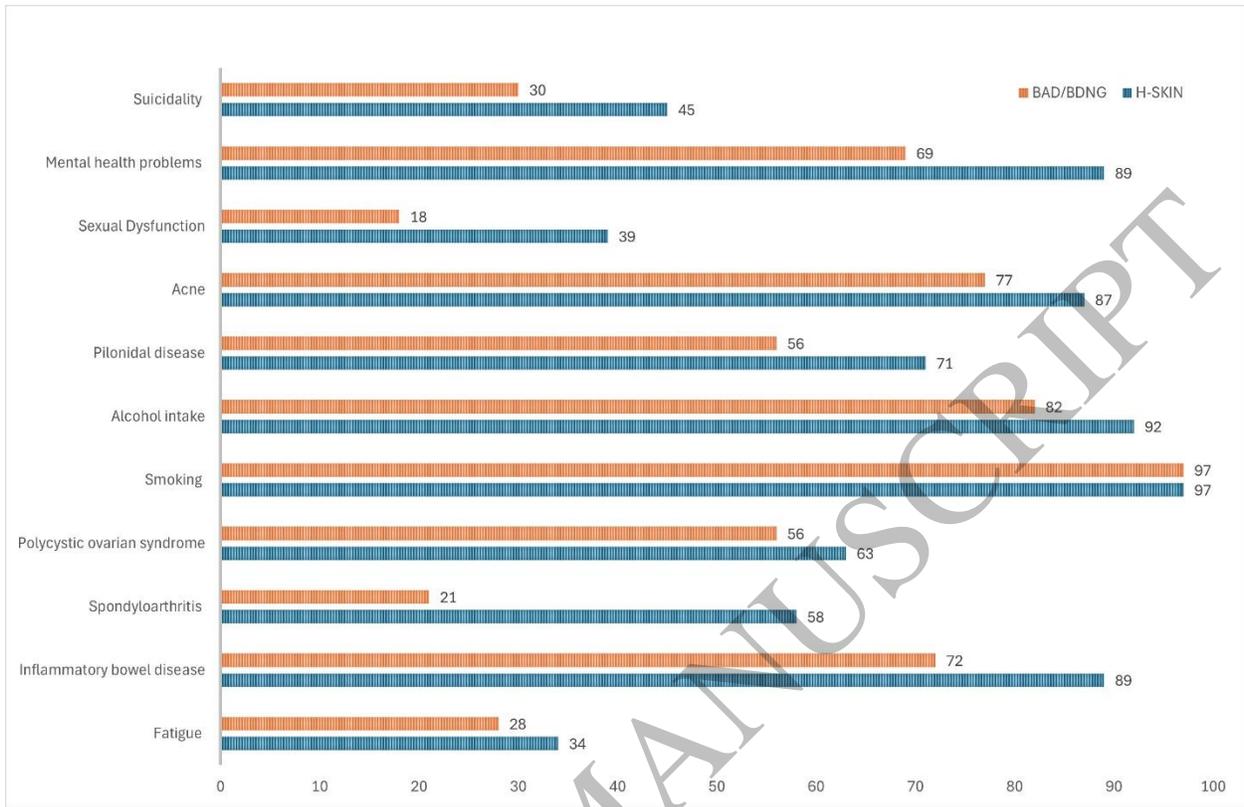


Figure 3
165x107 mm (x DPI)

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