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Published in:
British Journal of Dermatology

DOI:
10.1093/bjd/ljad454

Br J Dermatol 2024; **190**:510–518
https://doi.org/10.1093/bjd/ljad454
Advance access publication date: 17 November 2023

BJD
British Journal of Dermatology
Outcomes and Qualitative Outcomes

Global consensus process to establish a core dataset for hidradenitis suppurativa registries

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Abstract

Background Several registries for hidradenitis suppurativa (HS) already exist in Europe and the USA. There is currently no global consensus on a core dataset (CDS) for these registries. Creating a global HS registry is challenging, owing to logistical and regulatory constraints, which could limit opportunities for global collaboration as a result of differences in the dataset collected. The solution is to encourage all HS registries to collect the same CDS of information, allowing registries to collaborate.

Objectives To establish a core set of items to be collected by all HS registries globally. The core set will cover demographic details, comorbidities, clinical examination findings, patient-reported outcome measures and treatments.

Methods Beginning in September 2022, 20 participants – including both clinicians with expertise in HS and patient advocates – from eight countries across three continents participated in a Delphi process consisting of four rounds of voting, with all participants completing each round. A list of potential items for inclusion in the core set was generated from the relevant published literature, including systematic reviews of comorbidities in HS, clinical and examination findings, and epidemiology. For disease severity and progression items, the Hidradenitis SuppuraTiva Core outcome set International Collaboration (HiSTORIC) core set and other relevant instruments were considered for inclusion. This resulted in 47 initial items. Participants were invited to suggest additional items to include during the first round. Anonymous feedback was provided to inform each subsequent round of voting to encourage consensus.

Results The eDelphi process established a CDS of 48 items recommended for inclusion in all HS registries globally.

Conclusions The routine adoption of this CDS in current and future HS registries should allow registries in different parts of the world to collaborate, enabling research requiring large numbers of participants.

Accepted: 13 November 2023

What is already known about this topic?

- Several registries for hidradenitis suppurativa (HS) already exist, but there is no consensus on a core dataset (CDS).
- Creating a global HS registry is challenging, owing to logistical and regulatory constraints.
- Heterogeneity in recording of outcomes in a disease has been shown to hinder the comparison of results and pooling of data.

What does this study add?

- Our study provides a global consensus on a CDS to include in all HS registries worldwide, including demographic details, comorbidities, clinical examination findings, patient-reported outcome measures and treatments.

What are the clinical implications of this work?

- The routine adoption of the CDS in current and future HS registries will allow collaborative pooling of results on a project-by-project basis, enabling research requiring large sample sizes.

Hidradenitis suppurativa (HS) is a chronic inflammatory skin condition that presents with recurrent painful nodules, abscesses and tunnelling, predominantly in flexural sites.[1] The disease burden can be high and can profoundly affect the quality of life of patients and their families.[2–4] It has a global prevalence of approximately 1%.[5–9]

Many medical and surgical interventions have been tried for HS, including topical treatments, systemic antibiotics, retinoids, systemic immunosuppressive agents and biologics. Nonmedical interventions include laser therapy, deroofing procedures and regional excisions of the affected areas. There are limited data to support many of these treatment modalities and more research is required in this area.[10]

Registries for a disease allow prospective collection of real-world data, providing a larger dataset and longer-term follow-up when compared with relatively short randomized controlled trials with an explanatory rather than pragmatic design.[11] A pragmatic trial is defined as one that evaluates the efficacy of a treatment in routine clinical practice; in an explanatory trial, a treatment is evaluated under ideal conditions. Registries provide a database of individuals containing clearly defined sets of health and demographic data collected for a specific public health purpose.[12] Registries were initially created to collect epidemiological data but have now been applied diversely in disease prevention, pharmacovigilance, treatment efficacy, screening and healthcare planning.[11]

Several registries for HS already exist in Europe and the USA.[13–16] Creating a global HS registry is challenging, owing to logistical and regulatory constraints, which could limit opportunities for global collaboration as a result of differences in the dataset collected. One solution is to encourage all HS registries to collect the same core dataset (CDS) of information, allowing the registries to collaborate. Heterogeneity in the recording of outcomes in a disease has been shown to hinder the comparison of results and pooling of data, which may be needed to provide the large datasets for projects such as genetic studies and to investigate rare adverse treatment effects.[17] The development of an internationally agreed core set of variables is essential, as indicated by the guideline of the European Commission-funded PAtient REgistries iNiTiative joint action (PARENT JA).[18] Within HS, a core domain set exists from the Hidradenitis Suppurativa Core Outcomes Set International Collaboration (HiSTORIC) initiative for clinical trial outcomes.[19] There may be crossover between the core set for trials and the CDS for a registry; however, the registry needs to consider data beyond clinical outcomes, such as comorbidities, and some outcome instruments may be too time consuming for use in a registry setting.

The CDS does not seek to control the information collected by each individual registry; it simply defines the subset of essential items recommended for collection in HS registries. To be successful, and minimize the burden on registry participants and study staff, the CDS should be as concise as possible, while not omitting essential information. Our goal was to establish a CDS of items to be collected by all HS registries globally that covers demographic details, comorbidities, clinical examination findings, disease severity, progression and treatments.

Materials and methods

Study design

To establish a CDS an online Delphi exercise (hereafter referred to as 'eDelphi') was conducted.

The technique for an eDelphi comprises sequential questionnaires that are answered anonymously by participants with relevant expertise. After each questionnaire is completed, the group responses are fed back to participants. Bias is minimized as the responses are anonymized and there is no issue with participants being influenced by other members of the group who may dominate an in-person meeting setting. In subsequent rounds, participants have the option to keep or change their opinion and, gradually, a consensus evolves as the range of answers decreases and the group's opinions converge.[20]

Information sources

A list of potential items for inclusion in the core set was generated from the relevant published literature, including systematic reviews of comorbidities in HS, clinical and examination

findings, and epidemiology.[3,7,21,22] For disease severity and progression items, the HiSTORIC core set and other relevant instruments were considered for inclusion.[7,19,22–27]

Participants

For a CDS to have validity it is recommended that multiple stakeholder groups are included; patient participation is pivotal.[28,29] Participants were invited from two stakeholder groups: healthcare professionals (HCPs) and patient advocates.

Patient representatives were identified through patient associations and, in countries where no formal patient association existed, via dermatologists with a specialist interest in HS.

HCPs were identified as dermatologists with a special interest in HS. They all had at least 5 years of experience in managing patients with HS and had multiple publications in the field.

All those invited to participate agreed to take part in the process and are listed as authors of this paper.

Methods used to reach consensus on the core domain set

The eDelphi questionnaire was created using surveys.ac.uk and was distributed via email in September 2022. The questionnaire was piloted prior to distribution. It was sent to two dermatologists with an interest in HS research and who had previously taken part in multiple eDelphi processes. They were invited to provide feedback but no changes were recommended.

Each respondent was given a unique identifier to avoid submission of personal information, while ensuring only one submission was received from each participant. During the first round the details of the study and key objectives were outlined. Subsequent rounds reiterated the key objectives and explained the items that had already reached consensus in previous rounds. Participants were provided with histograms summarizing the spread of results for each item from the previous round, allowing them to compare their answer with the rest of the group, to encourage consensus. The full consensus process is illustrated in Figure 1. Provision was made for a potential in-person consensus meeting if items proved contentious and consensus by eDelphi was not possible; however, this option was not required.

Item scoring

Participants were asked to use a 9-point Likert scale for each item where one was 'strongly disagree with inclusion' in the core set for HS registries and nine was 'strongly agree with inclusion'. A score of zero was also available for those that were unsure. Responses of 'unsure' were excluded from the summary of results provided to participants in subsequent eDelphi rounds.

Definition of consensus

The definitions of consensus were defined a priori. The predefined criterion for inclusion was for at least 70% of respondents to score at least 7 for the item. The predefined criterion for exclusion was for at least 70% of respondents to score 1–3. Any other results were defined as no consensus being reached.

To reduce the risk of attrition bias, all participants were reminded in each round of the importance of completing all rounds of the eDelphi process. Reminder emails were sent to any nonresponders.

eDelphi round 1

The items in round 1 covered demographics, comorbidities, clinical examination findings and disease severity/progression. Forty-seven items were included in this round. A glossary of terms was provided to all patient representatives (Table S1; see Supporting Information). The glossary was created by means of a literature review.

In round 1, participants were given the option of suggesting additional items to be included in the dataset. These items were reviewed by the project steering committee to ensure they represented new items, and all unique suggested items were put forward for consideration in round 2.

eDelphi round 2

In round 2, all items that reached consensus in round 1 were omitted from further voting and a list of these items was provided at the end of the survey. For existing items that did not reach consensus in round 1, a histogram depicting the anonymous distribution of scores in round 1 was provided. For items that received predominantly low scores, the option to exclude the item was provided with a 'yes/no/don't know'

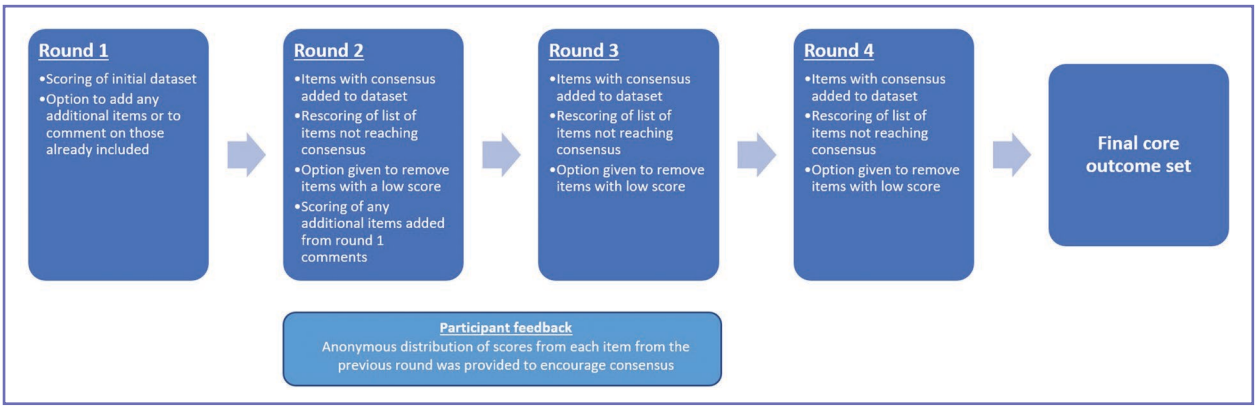

Figure 1 Summary of the eDelphi process.

option. The new items suggested at the end of round 1 were explained in the introduction to round 2 and included for consideration. Where items were similar or overlapping, for example measurement of current pain or worst pain in the last 24 h, the option was given to use one instead of the other.

eDelphi rounds 3 and 4

In rounds 3 and 4, participants were asked to review items that were close to consensus in conjunction with a histogram showing the distribution of results from the previous round. For items further from consensus, the option to remove the item was provided.

Results

Participants

In total, 4 patients and 16 clinicians, the latter including experience with paediatric patients and use of surgery, were included from 8 countries across 3 continents (Table 1). All participants contributed to each of the four rounds of the eDelphi process, achieving a 0% attrition rate.

Outcome scoring and feedback

A list of the 47 items initially included in the eDelphi exercise is shown in Table 2. Eight novel items were suggested by participants and were all considered valid items for consideration (Table 3). Seven items were excluded via the process (Tables 4, 5).

The final core domain set

The eDelphi process established a core set of 48 items recommended for inclusion in all HS registries. The core set is illustrated according to eDelphi round in Table 4 and the final core item set broken down into subdomains is provided in Table 5.

Table 1 Demographics of 20 participants in a Delphi process to establish a core set of items to be collected by all hidradenitis suppurativa registries globally

Variable	*n* (%)
Sex	
Male	11 (55)
Female	9 (45)
Dermatologist	16 (80)
Patient advocate	4 (20)
Geographical origin	
USA	5 (35)
The Netherlands	3 (15)
Denmark	3 (15)
UK	2 (10)
Ireland	2 (10)
Spain	1 (5)
Singapore	2 (10)
Australia	1 (5)

Table 2 Initial items included in round 1 of a Delphi process to establish a core set of items to be collected by all hidradenitis suppurativa (HS) registries globally

Area	Items included
Demographics	Sex
	Age
	Race (EHSCS)
	Smoking status
	BMI
	WC (part of metabolic syndrome)
	Family history of HS in first-degree relative
	Socioeconomic status
	Date of onset
	Date diagnosed with HS
Comorbidities	T2DM
	Hypertension
	Dyslipidaemia
	Cardiovascular disease (IHD and/or cerebrovascular disease)
	Depression
	Anxiety
	Crohn disease
	Ulcerative colitis
	Psoriasis (including chronic plaque, flexural, paradoxical secondary to biologic therapy)
	Inflammatory arthritis (ankylosing spondylosis, RA, PsA)
	PCOS
	Down syndrome
	Obstructive sleep apnoea
	Cutaneous SCC linked to HS
	PG
	Syndromes: PASH; PAPASH; PASS
	Thyroid disease
	Renal amyloidosis
	NAFLD
Comorbidities relevant to phenotyping	Pilonidal sinus
	Acne conglobata
	Acne vulgaris
	Scalp folliculitis/folliculitis decalvans
Clinical examination findings	Skin regions affected (left/right): axilla, breast/chest, buttock, perianal/perineal, groin/medial thigh, genital, other (posterior neck, trunk, nonmedial thighs)
	Presence and location of folliculitis
	Presence and location of epidermoid cysts
	Presence and location of PG-type lesions
	Presence and location of open comedones
	Hurley stage in each affected region
	Refined Hurley staging
	IGA
	PGA
	HiSQOL-17
	HiSQOL-mini
	DLQI
	Current pain NRS 0–10
	Total drainage NRS 0–10

BMI, body mass index; DLQI, Dermatology Life Quality Index; EHSCS, Eumelanin Human Skin Colour Scale; HiSQOL, Hidradenitis Suppurativa Quality of Life; IGA, Investigator Global Assessment; IHD, ischaemic heart disease; NAFLD, nonalcoholic fatty liver disease; NRS, numerical rating scale; PAPASH, pyogenic arthritis, acne, PG and HS; PASH, PG, acne conglobata and HS; PASS, PG, acne vulgaris, HS and ankylosing spondylitis; PCOS, polycystic ovary syndrome; PG, pyoderma gangrenosum; PGA, Patient Global Assessment; PsA, psoriatic arthritis; RA, rheumatoid arthritis; SCC, squamous cell carcinoma; T2DM, type 2 diabetes mellitus; WC, waist circumference.

Table 3 Additional items suggested by participants added in round 2 of a Delphi process to establish a core set of items to be collected by all hidradenitis suppurativa registries globally

Worst pain in the last 24 h
Inflammatory nodule and abscess count
Inflamed tunnels count
Cribriform scarring
Current medical and surgical treatment
Previous medical and surgical treatment (recorded at baseline)
Odour NRS 0–10
Fatigue (instrument to be decided)

NRS, numerical rating scale.

Changes to original plan

Provision was made for a consensus meeting at the European Hidradenitis Suppurativa Foundation annual conference in 2023; however, consensus was reached on all items without a face-to-face meeting by the addition of a fourth round of eDelphi.

No items reached the predefined criteria of 'consensus out'. To ensure that the core set was as concise as possible, items with low levels of support in the previous survey round were highlighted for potential omission with the use of a 'yes/no' question for exclusion.

Discussion

We used a rigorous, iterative and inclusive approach to achieve consensus among an international group of HCPs and patients with expertise in HS. While keeping participants engaged with an eDelphi process can be challenging, all 20 participants provided comprehensive answers across all four eDelphi rounds, avoiding attrition bias. All stakeholders were in close agreement with the final CDS. The 0% rate for attrition illustrates the willingness of both HCPs and patients to support research in HS to improve health outcomes, despite no incentives being offered.

Adopting a minimum CDS for all global HS registries allows for collaboration between registries for projects such as genome-wide associated studies, phenotype–genotype correlation and biomarker studies, where large patient numbers may be needed. Table 4 lists the final global CDS for HS registries divided into six subdomains: demographics, comorbidities, associated diseases, clinical examination, patient-reported outcomes and treatment.

The Eumelanin Human Skin Colour Scale, a new 5-point standard nomenclature for physicians to use to describe human constitutive skin colour, published in 2022, achieved consensus in the first round. The rapid consensus for this item highlighted the increased understanding and recognition of better representation of patients with skin of colour in research projects.[30,31] This is important because HS is thought to be particularly prevalent in African American and other populations with skin of colour, based on epidemiological studies.[32] These studies have not been reproduced comprehensively using data from the Global South as yet, and questions regarding genetic and environmental factors remain; however, the Global Hidradenitis Suppurativa Atlas (GHISA) project is coordinating a worldwide prevalence study.[33,34]

HS has been established as a multisystem disease and the inclusion of multiple comorbidities in the CDS recognizes this.[3,35] By collecting data on these comorbidities, and especially those disease associations relevant to phenotyping, we can better understand the disease and its subtypes in the future. The ultimate aim is to identify patients who will respond best to a particular intervention, providing personalized therapy, and to identify those patients whose disease may rapidly progress and so require early intervention with the most effective therapies.

Clinical examination findings included in the CDS highlight that some features of the disease, such as cribriform scarring, might be indicators of disease severity and rapid progression and further data collected through registries on these elements will aid prognosis predictions in the future.[36]

Fatigue as a symptom in HS has not been widely investigated; however, it is included along with drainage in the HiSTORIC symptom domain for HS trials.[19] Incorporating it in the CDS as a patient-reported outcome both recognizes its importance to patients with HS and allows data to be collected to research the impact of fatigue in HS.[37]

While we lacked representation from Africa and South America, we did have representation from eight countries in three continents and we included participants from all regions with an existing registry. This wide representation strengthens our recommendations and, importantly, patients were actively involved throughout the process. All stakeholders have been encouraged to endorse the recommendations of the CDS as it will only be impactful if it is consistently implemented.

Future work includes the creation of a UK and Ireland HS registry that will incorporate the CDS. This will allow piloting of the dataset to ensure it is feasible from a patient perspective and does not overburden colleagues working in busy clinical settings.

In conclusion, we present a global CDS for HS with the intention of it being adopted by all registries worldwide, to allow for the pooling of registry data globally to help answer important research questions that remain in HS.

Acknowledgements

We thank all the participants who took part in the eDelphi process for their willingness to participate and for their time and patience with the process.

Funding sources

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Conflicts of interest

H.E.W. has received travel expenses and/or speaker's honoraria from UCB, Novartis, AbbVie and LEO. N.S.C. has received fees from AbbVie, Johnson & Johnson, Sanofi, Pfizer, Novartis and DKSH for participation in advisory boards; investigator fees for clinical trials from AbbVie, Novartis, Sanofi and Boehringer Ingelheim; and speaker honoraria from Galderma, Johnson & Johnson, Janssen, LEO Pharma, Lion Corporation and Sanofi. J.W.F. has conducted

Table 4 Items that reached consensus in or were excluded by eDelphi rounds in a process to establish a core set of items to be collected by all hidradenitis suppurativa (HS) registries globally

Round	Items reaching consensus	Items excluded
1	• Sex • Age • Race (include EHSCS) • Smoking status • BMI • Family history of HS in a first-degree relative • Date of onset • Date diagnosed with HS • T2DM • Hypertension • Dyslipidaemia • CV disease (IHD and/or cerebrovascular disease) • Depression • Anxiety • Crohn disease • Ulcerative colitis • Psoriasis (including chronic plaque, flexural, paradoxical secondary to biologic therapy) • Inflammatory arthritis (ankylosing spondylosis, RA, PsA) • PCOS • Cutaneous SCC linked to HS • PG • Syndromes: PASH; PAPASH; PASS • Pilonidal sinus • Acne conglobata • Acne vulgaris • Scalp folliculitis/folliculitis decalvans • Skin region affected: left/right axilla, breast/chest, buttock, perianal/perineal, groin/medial thigh, genital, other (posterior neck, trunk, nonmedial thighs) • Presence and location of open comedones (pores) • Hurley stage in each affected region • HS-IGA[24] • HiSQOL-17 • DLQI • Current pain NRS 0–10 • Total drainage NRS 0–10	
2	• Down syndrome • Anaemia • Patient global QoL assessment[25] • HiSQOL-Mini • Inflammatory nodule and abscess count • Tunnel count • Current medical and surgical treatment • Previous medical and surgical treatment (recorded at baseline) • Presence and location of folliculitis • Epidermoid cysts	• Amyloidosis
3	• Metabolic syndrome • Fatigue • Worst pain in last 24 h NRS 0–10	• Current pain Numerical Rating Scale (NRS) 0–10
4	• NAFLD • Refined Hurley staging • Cribriform scarring	• Socioeconomic status • Thyroid disease • Odour NRS 0–10 • Pyogenic granulomas • Obstructive sleep apnoea

BMI, body mass index; CV, cardiovascular; DLQI, Dermatology Life Quality Index; EHSCS, Eumelanin Human Skin Colour Scale; HiSQOL, Hidradenitis Suppurativa Quality of Life; IGA, Investigator Global Assessment; IHD, ischaemic heart disease; NAFLD, nonalcoholic fatty liver disease; NRS, numerical rating scale; PAPASH, pyogenic arthritis, acne, PG and HS; PASH, PG, acne conglobata and HS; PASS, PG, acne vulgaris, HS and ankylosing spondylitis; PCOS, polycystic ovary syndrome; PG, pyoderma gangrenosum; PsA, psoriatic arthritis; QoL, quality of life; RA, rheumatoid arthritis; SCC, squamous cell carcinoma; T2DM, type 2 diabetes mellitus.

advisory work for Janssen, Boehringer Ingelheim, Pfizer, Kyowa Kirin, LEO Pharma, Regeneron, ChemoCentryx, AbbVie, Azora, Novartis and UCB; has participated in trials for Pfizer, UCB, Boehringer Ingelheim, Eli Lilly, CSL and Azora; and has received research support from Ortho Dermatologics, Sun Pharma, LEO Pharma, UCB and La Roche Posay. A. Garg is an advisor for AbbVie, Aclaris Therapeutics, AnaptysBio, Aristea Therapeutics, Boehringer Ingelheim, Bristol Myers Squibb, Incyte, Insmed, Janssen, Novartis, Pfizer, Sonoma Biotherapeutics, UCB, Union Therapeutics, Ventyx Biosciences and Viela Biosciences, and receives honoraria; receives research grants from

Table 5 Final global core dataset for hidradenitis suppurativa (HS) registries

Core dataset subdomain	
Demographics	Sex
	Age
	Race (EHSCS)
	Smoking status
	BMI
	Family history of HS in first-degree relative
	Date of onset
	Date diagnosed with HS
Comorbidities	T2DM
	Hypertension
	Dyslipidaemia
	CV disease
	Depression
	Anxiety
	Crohn disease
	Ulcerative colitis
	Psoriasis
	Inflammatory arthritis
	PCOS
	Cutaneous SCC linked to HS
	PG
	Syndromes: PASH, PAPASH, PASS
	NAFLD
	Metabolic syndrome
	Down syndrome
	Anaemia
Comorbidities relevant to phenotyping	Pilonidal sinus
	Acne conglobata
	Acne vulgaris
	Scalp folliculitis/folliculitis decalvans
Clinical examination findings	Skin regions affected
	Hurley stage in each affected region
	Refined Hurley staging
	Inflammatory nodule and abscess count
	Draining tunnel count
	Nondraining tunnel and noninflammatory nodule count[a]
	Presence and location of folliculitis
	Cribriform scarring
	Epidermoid cysts
	Presence and location of open comedones
PRO measures	HiSQOL-17 (and HiSQOL-Mini subset of items)
	DLQI
	Fatigue
	Worst pain in last 24 h NRS 0–10
	Total drainage NRS 0–10
	Patient global QoL assessment
Current/previous treatment	Current medical and surgical treatment
	Previous medical and surgical treatment

BMI, body mass index; CV, cardiovascular; DLQI, Dermatology Life Quality Index; EHSCS, Eumelanin Human Skin Colour Scale; HiSQOL, Hidradenitis Suppurativa Quality of Life; NAFLD, nonalcoholic fatty liver disease; NRS, numerical rating scale; PAPASH, pyogenic arthritis, acne, PG and HS; PASH, PG, acne conglobata and HS; PASS, PG, acne vulgaris, HS and ankylosing spondylitis; PCOS, polycystic ovary syndrome; PG, pyoderma gangrenosum; PRO, patient-reported outcome; QoL, quality of life; SCC, squamous cell carcinoma; T2DM, type 2 diabetes mellitus. [a]HS Investigator Global Assessment.

AbbVie, UCB, the National Psoriasis Foundation and the CHORD COUSIN Collaboration (C3); and is co-copyright holder of the Hidradenitis Suppurativa Investigator Global Assessment (HS-IGA) and Hidradenitis Suppurativa Quality of Life (HiSQOL) instruments. A. Gierbolini is a patient advisory board member for Novartis and UCB. B.H. reports fees paid to her institution from Janssen-Cilag (advisory boards, educational grants, consultations, investigator initiative studies), AbbVie (advisory boards, educational grants, consultations, investigator initiative studies), Novartis Pharma (advisory boards, consultations, investigator initiative studies), UCB Pharma (advisory boards, consultations), LEO Pharma (consultations), Solenne (investigator initiative studies), Celgene (consultations, investigator initiative studies), Akari Therapeutics (consultations, investigator initiative studies), Philips (consultation), Roche (consultation), Regeneron (consultation), Sanofi (consultation) and Argenx (advisory boards, consultations). G.B.J. reports grants and personal fees from AbbVie, personal fees from Coloplast, personal fees from ChemoCentryx, personal fees from LEO Pharma, grants from the LEO Foundation, grants from Afyx, personal fees from Incyte, grants and personal fees from InfaRx, grants from Janssen-Cilag, grants and personal fees from Novartis, grants and personal fees from UCB, grants from CSL Behring, grants from Regeneron, grants from Sanofi, personal fees from Kymera and personal fees from VielaBio. B.K. has acted as an investigator, received grants and/or honoraria from AbbVie, Almirall, Amgen, AstraZeneca, Biogen, Bristol Myers Squibb, Celgene, Janssen, Lilly, LEO Pharma, Merck, MoonLake, Novartis, Pfizer and UCB Pharma. J.K. is on the advisory boards for AbbVie, Incyte, Novartis and UCB; is a consultant for AbbVie, Alumis, DermTech, Guidepoint, Incyte, Insmed, Janssen, MoonLake, Novartis and UCB; is a speaker for AbbVie, Novartis, UCB and Janssen; and co-inventor of the HiSQOL and Hidradenitis Suppurativa Area and Severity Index Revised (HASI-R). M.A.L. has served on advisory boards for AbbVie, InflaRx, Janssen, Novartis, UCB and Viela Bio; has consulted for Almirall, BSN Medical, Incyte, Janssen, Kymera, Phoenicis and XBiotech; and is on the board of the Hidradenitis Suppurativa Foundation, a voluntary position. A.M. is a member of the European Hidradenitis Suppurativa Foundation; and has acted as a consultant, advisory board member and investigator for, and has received honoraria from, Novartis, AbbVie, Janssen Cilag, UCB, Lilly, LEO Pharma, L'Oréal, Sanofi, Sandoz, Galderma and Amgen. B.M.M. has received disease-related honoraria from Novartis and UCB. H.B.N. has received grant support from AbbVie; consulting fees from 23andme, AbbVie, Aristea Therapeutics, Nimbus Therapeutics, Medscape, Sonoma Biotherapeutics, DAVA Oncology, Boehringer Ingelheim, UCB and Novartis; investigator fees from Pfizer; and holds shares in Radera. H.B.N. is also an Associate Editor for *JAMA Dermatology* and a board member of the Hidradenitis Suppurativa (HS) Foundation. H.H.O. has received speaker's honoraria from AbbVie, Eli Lilly, Galderma, Janssen, LEO Pharma and Novartis; has been an advisory board member for Boehringer Ingelheim; and has been a researcher for Novartis and Pfizer. E.P. has received honoraria as a consultant, advisory board member, speaker and/or Principal Investigator for AbbVie, Almirall, Amgen, Astra-Zeneca, Celgene, ChemoCentryx, InflaRx, Janssen-Cilag, Novartis, Pfizer and UCB; and has received investigator-initiated grant support (paid to Erasmus University) from AbbVie, Astra Zeneca, Celgene, CHDR, Kymera, Novartis, Pfizer, Janssen-Cilag and UCB. C.J.S. is a speaker for AbbVie and Novartis; has consulted for AbbVie, Novartis, InflaRx, UCB, Incyte, Sonoma Biotherapeutics and Alumis; is an investigator for AbbVie, Novartis, InflaRx, UCB, Incyte and ChemoCentryx; has received grant funding from AbbVie; and is on the board

of the HS Foundation, an unpaid position. L.T. has received speaker honoraria from UCB; has had travel expenses covered by AbbVie and Janssen; and is co-copyright holder of HiSQOL. H.H.d.V.Z. has received honoraria as speaker or as member of an advisory board for UCB, Novartis, AbbVie, InflaRX and Insmed. B.V. has received travel expenses from Novartis and Boehringer Ingelheim, and is a co-copyright holder of HiSQOL; her association has received grant funding or fees for patient advisory boards from AbbVie, UCB, Novartis and Boehringer Ingelheim. J.R.I. receives a stipend as Editor-in-Chief of the *British Journal of Dermatology* and an authorship honorarium from UpToDate. He is a consultant for AbbVie, Boehringer Ingelheim, ChemoCentryx, Citryll, Novartis and UCB Pharma, and has served on advisory boards for Insmed, Kymera Therapeutics and Viela Bio. He is co-copyright holder of the HiSQOL, HS-IGA and patient global quality of life assessment instruments for HS. His department receives income from copyright of the Dermatology Life Quality Instrument (DLQI) and related instruments. A. Gibbons declares no conflicts of interest.

Data availability

The data underlying this article are available in the article and the Supporting Information.

Ethics statement

No ethical approval was required because participants were either clinicians or patient advocates, providing their opinions only.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website.

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