Acceptability and Usability of the Electronic Hidradenitis Suppurativa Quality of Life Questionnaire

Joslyn Kirby,[1] Valerie Ciaravino,[2] Robert Rolleri,[3] Ingrid Pansar,[4] Natalie Taylor,[5] John R Ingram[6]

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Objectives

An observational, qualitative study was conducted to establish the acceptability and usability of the electronic Hidradenitis Suppurativa Quality of Life Questionnaire (eHiSQOL) among patients with moderate-to-severe hidradenitis suppurativa (HS).

Background

- HS is a debilitating skin disease and the high burden of the disease can have a significant negative impact on the physical and mental wellbeing of patients.[1]
- The Hidradenitis Suppurativa Quality of Life Questionnaire (HiSQOL) is an HS-specific instrument developed to measure the impact of HS on patients' quality of life.[2]
- Psychometric validation of the hand-written version of the questionnaire is ongoing.[3,4]
- In line with FDA guidelines on instrument modification, evidence of the acceptability and usability of the electronic version of the HiSQOL is needed to ensure the instrument is well defined and reliable to support labelling claims.[5,6]

Methods

- One-on-one semi-structured video interviews were conducted among patients with moderate-to-severe HS (at screening) recruited from the Penn State Hershey Medical Center (USA) and lasted approximately 90 minutes each.
- Interviews were conducted in US English, audio-recorded, and then subsequently transcribed.
- Interviews included training on the use of the electronic device, completion of the eHiSQOL, and collecting overall impressions and feedback on the acceptability and usability of the questionnaire.
- The eHiSQOL includes 17 items assessed over the past 7 days on a Likert-type scale with 5–7 response options and was completed on a tablet (**Figure 1, 2**).
- Items are grouped according to symptoms, psychosocial impact, and activities and adaptations subscales.
- Item scores range from 0 (not at all) to 4 (extremely) and are summed to generate a total score ranging from 0–68, with higher scores indicating a greater impact on quality of life.[3]

Results

- A total of 20 patients with HS were interviewed. The median age (range) was 41.5 (20.0–64.0) years, 80% of participants were female, and 75% reported living with an HS diagnosis for >5 years.
- The mean (standard deviation) eHiSQOL total score for the interviewed patients was 27.3 (17.5; **Table 1**).
- The median completion time for the eHiSQOL was 3 minutes and 8 seconds, ranging from 49 seconds to 11 minutes and 13 seconds.
- Overall, all patients considered the eHiSQOL easy to use.
- Half of the patients spontaneously reported that the eHiSQOL was "simple", "clear", "easy", or "concise".
- When questioned, the other half reported that they liked the content, diverse questions, and applicable response options.
- All patients reported having no difficulty in understanding how to complete the questionnaire.
- None of the patients suggested changing the on-screen appearance of the questions or response options, and all were happy with the response scale layout and presentation.
- Four patients (20%) suggested that they would have preferred a larger font size and two patients (10%) reported issues moving between screens due to difficulty getting buttons to respond.

Conclusions

This study provides evidence of the acceptability, ease of use, and usability of the eHiSQOL.

These properties were confirmed regardless of age, gender, or level of familiarity with the devices in this sample of patients with moderate-to-severe HS.

Summary

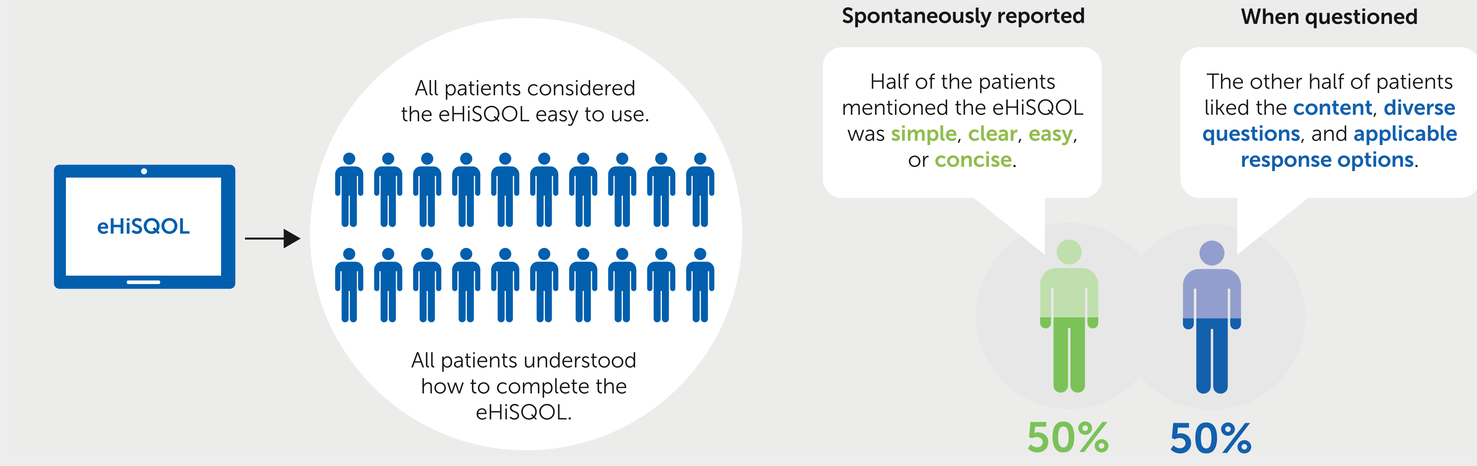


Figure 1 HiSQOL questionnaire

This questionnaire is designed to measure the impact of hidradenitis suppurativa (HS) also known as acne inversa, on you.

PLEASE READ THESE DIRECTIONS:

It is important to:
1. Think about your HS over the past 7 days.
2. Think about your HS only, not another condition.
3. For each item select the single best option.

In the past 7 days, how much has your HS impacted:

	UNABLE TO DO due to my HS	Extremely	Very much	Moderately	Slightly	Not at all
Walking (not for exercise)	○	○	○	○	○	○
Exercising (for example: swimming, jogging, biking, yoga, aerobics)	○	○	○	○	○	○
Sleeping		○	○	○	○	○
Washing yourself		○	○	○	○	○
Getting dressed		○	○	○	○	○
Concentrating		○	○	○	○	○

In the past 7 days, how has your HS influenced:

	Extremely	Very much	Moderately	Slightly	Not at all
What you wear to avoid discomfort	○	○	○	○	○

In the past 7 days, due to HS, how impacted have you been by:

	Extremely	Very much	Moderately	Slightly	Not at all
Pain	○	○	○	○	○
Itch	○	○	○	○	○
Drainage	○	○	○	○	○
Odour	○	○	○	○	○

In the past 7 days, how much has HS caused you to feel:

	Extremely	Very much	Moderately	Slightly	Not at all
Down or depressed	○	○	○	○	○
Embarrassed	○	○	○	○	○
Anxious or nervous	○	○	○	○	○

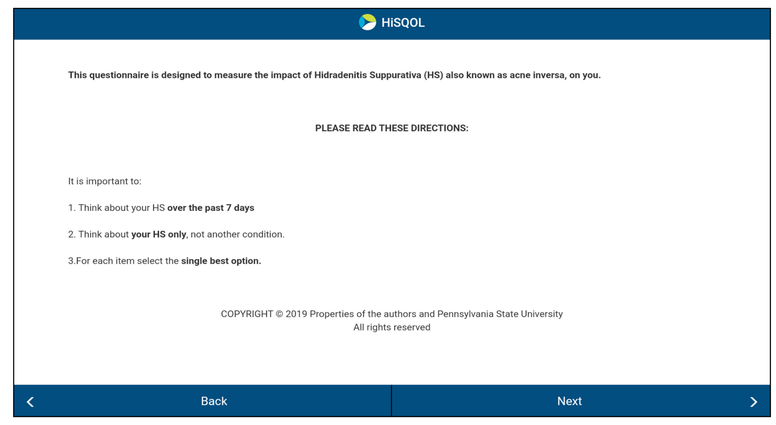
In the past 7 days, how much has HS:

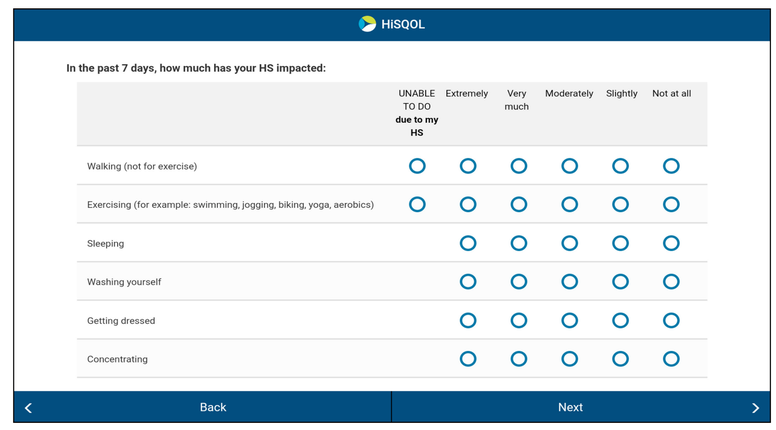
	I am not sexually active	UNABLE TO DO due to my HS	Extremely	Very much	Moderately	Slightly	Not at all
Made sexual activities difficult	○	○	○	○	○	○	○
Affected your desire for sexual activities			○	○	○	○	○

In the past 7 days, how much has HS influenced:

	I do not work or study	UNABLE TO DO due to my HS	Extremely	Very much	Moderately	Slightly	Not at all
Your ability to work or study	○	○	○	○	○	○	○

Figure 2 Screenshots of the eHiSQOL questionnaire as viewed on the tablet





Screenshots of only the first two pages of the electronic questionnaire are shown.

Table 1 eHiSQOL summary scores (N=16)[a]

Item	Mean (SD)	Median (Range)
eHiSQoL Total Score	27.3 (17.5)	20.5 (4.0–60.0)
Symptoms[b]	7.4 (4.5)	6.0 (2.0–16.0)
Psychosocial[c]	6.6 (5.7)	5.0 (0.0–18.0)
Activities and Adaptations[d]	13.3 (8.4)	12.0 (0.0–28.0)

[a] Data were not recorded for four participants due to interviewer oversight. [b] The sub-scale scores range from 0–16 for symptoms. [c] The sub-scale scores range from 0–20 for psychosocial impact. [d] The sub-scale scores range from 0–32 for activities and adaptations.[3]

eHiSQOL: electronic Hidradenitis Suppurativa Quality of Life Questionnaire; **HiSQOL**: Hidradenitis Suppurativa Quality of Life Questionnaire; **HS**: hidradenitis suppurativa; **SD**: standard deviation.

Institutions: [1]Penn State University, Hershey PA, USA; [2]UCB Pharma, Colombes, France; [3]UCB Pharma, Morrisville, NC, USA; [4]UCB Pharma, Brussels, Belgium; [5]Evidera, Bethesda, MD, USA; [6]Cardiff University, Cardiff, UK.

References: [1]Ingram JR, et al. *J Eur Acad Dermatol Venereol*. 2022;36(9):1597–605. [2]Thorlacius L, et al. *Skin Appendage Disord*. 2019;5(4):221–29. [3]Kirby JS, et al. *Br J Dermatol*. 2020;183(2):340–48. [4]Kirby, JS et al. *Br J Dermatol*. 2021;184(4):681–87. [5]US Food and Drug Administration. 2020. Available from: https://www.fda.gov/media/139088/download (accessed 19/08/22). [6]Coons SJ, et al. *Value Health*. 2009;12(4):419-29. **Author Contributions:** Substantial contributions to study conception and design: **JRI**, **VC**, **RR**, **NT**, **JK**; substantial contributions to analysis and interpretation of the data: **JRI**, **VC**, **RR**, **IP**, **NT**, **JK**; drafting the article or revising it critically for important intellectual content: **JRI**, **VC**, **RR**, **IP**, **NT**, **JK**; final approval of the version of the article to be published: **JRI**, **VC**, **RR, IP**, **NT**, **JK**. **Author Disclosures:** **JK**: Speaker for AbbVie, Janssen and UCB Pharma; received grants from Incyte and served as a consultant for AbbVie, ChemoCentryx, InflaRx, Incyte, MoonLake, Novartis, Janssen and UCB Pharma. **VC**, **RR**, **IP**: Employees and shareholders of UCB Pharma. **NT**: Employee of Evidera. **JRI**: Receives a stipend as Editor-in-Chief of the British Journal of Dermatology and an authorship honorarium from UpToDate; consultant for Boehringer Ingelheim, ChemoCentryx, Novartis and UCB Pharma and has served on advisory boards for Insmed, Kymera Therapeutics and Viela Bio, all in the field of hidradenitis suppurativa (HS); co-copyright holder of the Hidradenitis Suppurativa Quality of Life Questionnaire (HiSQOL), Investigator Global Assessment and Patient Global Assessment instruments for HS; his department receives income from copyright of the Dermatology Life Quality Instrument (DLQI) and related instruments. **Acknowledgements:** This study was funded by UCB Pharma. The authors acknowledge Paul Gillard, Thermo Fisher Scientific, Brussels, Belgium for contributions to this study and Susanne Wiegratz, MSc, UCB Pharma, Monheim, Germany, for publication coordination. Medical writing and editorial assistance were provided by Zoha Naveed, MBiochem, Costello Medical, London, UK, and funded by UCB Pharma.

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