

Real-world clinical characteristics and demographics of patients with hidradenitis suppurativa in Canada using AI-extracted data

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Objective

To describe the demographic and clinical characteristics of patients with hidradenitis suppurativa (HS) in the Epidemiology and Treatment of Hidradenitis Suppurativa in Canada (ETHiC) study, including those with moderate/severe disease and those initiating biologic therapy.

Background

- HS is a chronic, debilitating skin condition characterized by recurrent nodules, abscesses, draining and non-draining tunnels in the intertriginous areas.
- HS imposes substantial physical, psychological, and economic burden.
- Despite increasing global research, data on patients with HS in Canada remain limited.¹⁻³
- The ETHiC study is based on the largest longitudinal real-world dataset of patients with HS in Canadian community dermatology clinics.

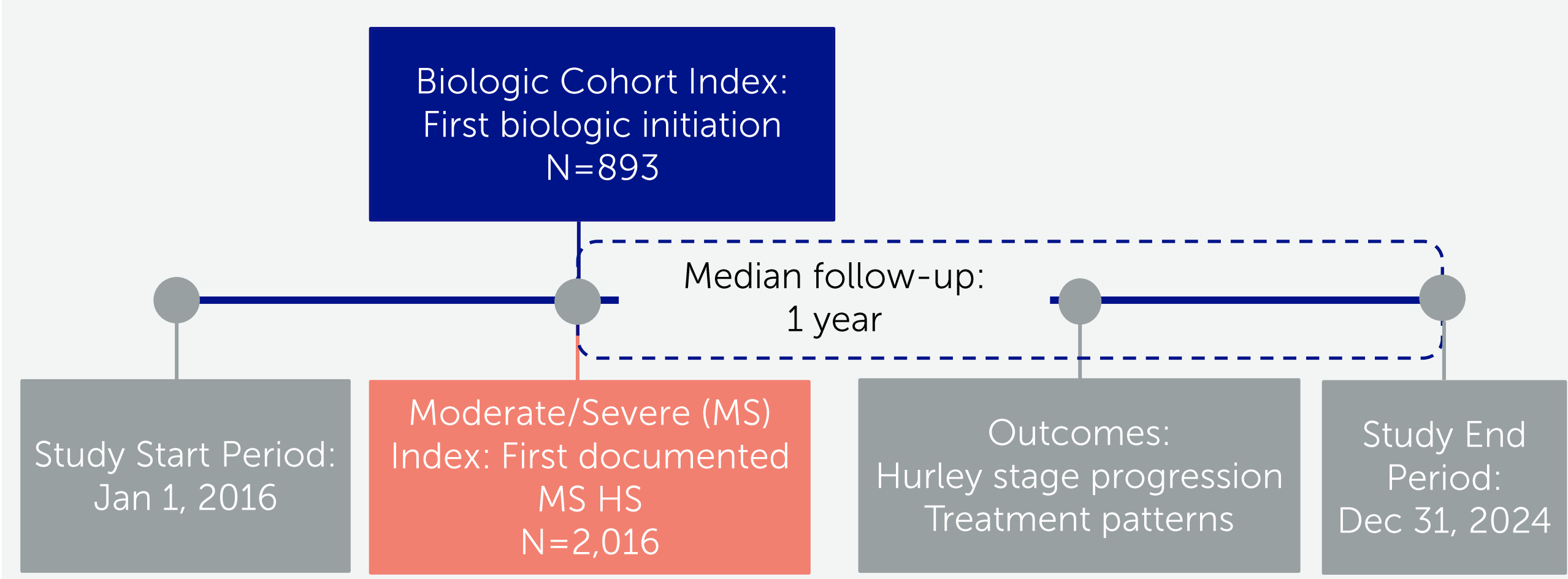
Methods

- ETHiC is a retrospective, multi-centre, non-interventional cohort study using electronic health records (EHRs) from community dermatology clinics across Canada.
- The study population includes adults with dermatologist-confirmed HS between January 1, 2016, and December 31, 2024.
- Validated artificial intelligence data extraction engine DARWENTTM abstracted clinical variables from EHRs.
- Patient data were analyzed across cohorts:
 - (1) those initiating biologic therapy
 - (2) those with moderate/severe HS (defined as Hurley stage II or III, clinician-reported disease as moderate/severe HS, or initiation of biologic therapy for HS).
- The cohorts were not mutually exclusive, and patients could be included in both cohorts.
- Characteristics were summarized using descriptive statistics. Time to Hurley stage increase (stage II to III) and time to biologic initiation following identification of moderate/severe disease were estimated using Kaplan-Meier methods.

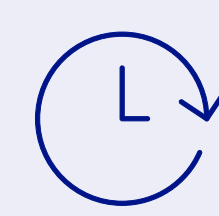
Results

- A total of 5,438 patients with HS were eligible for the study. Among these, 893 initiated biologic therapy and 2,016 had moderate/severe disease.
- Baseline characteristics are presented in Table 1 and Figure 1. In both cohorts, the axilla and groin were the most affected body sites and among patients with a reported Hurley stage, most were stage II.
- Median time from symptom onset to dermatologist-confirmed HS was 6 years in both cohorts.
- Among the moderate/severe cohort, median time to biologic initiation was 7.1 months. After 5 years, 26.0% of patients had not received biologic therapy (Figure 2).
- In the moderate/severe cohort, among patients with at least two recorded disease severity assessments, median time to increase from Hurley stage II to Hurley stage III was 4.9 years, while 25.0% of patients increased within 2.3 years (Figure 3).

Summary



ETHiC represents one of the largest real-world study cohorts of HS patients



6-year median diagnostic delay
• Patients may miss the window of opportunity to initiate disease-modifying treatment to prevent disease progression and damage



4.9-year median Hurley stage progression from stage II to III
• Need for advances in disease management

Conclusion

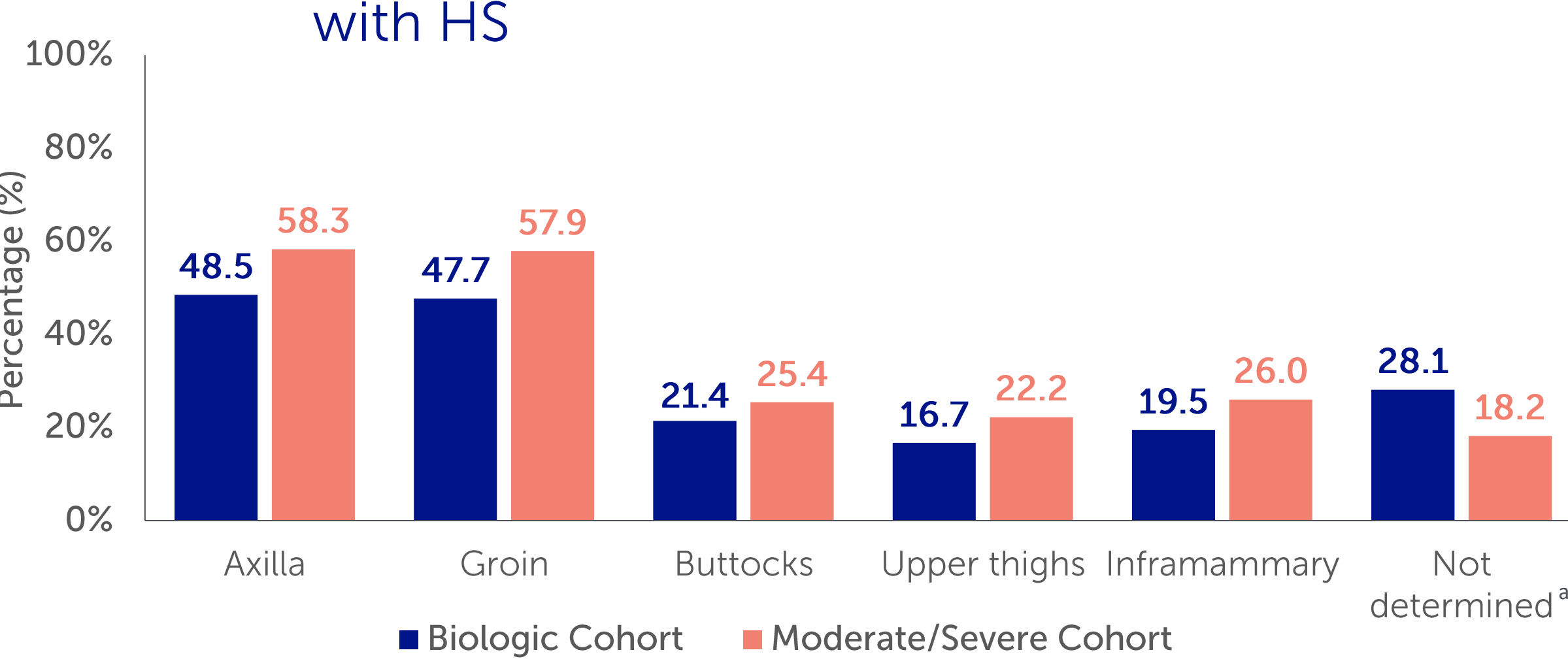
ETHiC represents one of the largest real-world study cohorts of HS patients. This study revealed substantial disease burden and significant diagnostic delays among Canadian patients with HS that may contribute to disease progression and impact quality of life, highlighting the unmet need for earlier recognition and treatment.

Table 1 Demographics and clinical characteristics among patients with HS

	Biologic Cohort N=893	Moderate/Severe Cohort N=2,016
Age at index, years		
Median (IQR)	39.0 (30.0–48.0)	37.0 (29.0–47.0)
Sex (n, %)		
Male	290 (32.5%)	570 (28.3%)
Female	603 (67.5%)	1,446 (71.7%)
Follow-up duration, years		
Median (IQR)	1.0 (0.0–3.0)	1.0 (0.0–2.0)
Hurley stage at index (n, %)		
I	33 (10.0%)	40 (3.0%)
II	184 (55.6%)	1,033 (76.5%)
III	114 (34.5%)	277 (20.5%)
Missing	562	666
Time since symptom onset to date first seen by dermatologist for HS, years		
n	477	1,139
Median (IQR)	6.00 (2.00–15.00)	6.00 (2.00–15.00)
Missing	416	877
Number of pre-specified body sites affected at index (including axilla, groin, buttocks, upper thighs, and inframammary) (n, %)		
<3	429 (48.0%)	953 (47.3%)
≥2	432 (48.4%)	1,200 (59.5%)
≥3	213 (23.9%)	696 (34.5%)
Not determined ^a	251 (28.1%)	367 (18.2%)
History of notable conditions prior to or at index date (n, %)		
Depression	95 (10.6%)	196 (9.7%)
Anxiety	100 (11.2%)	189 (9.4%)
Diabetes	84 (9.4%)	188 (9.3%)
Plaque psoriasis	120 (13.4%)	183 (9.1%)
Inflammatory bowel disease	54 (6.0%)	105 (5.2%)
Smoking status at index date (n, %)		
Current	256 (60.0%)	660 (60.4%)
Former	29 (6.8%)	76 (7.0%)
Never	142 (33.3%)	356 (32.6%)
Missing	466	924
Treatments received prior to index date (n, %)		
Any HS-related treatment	468 (52.4%)	378 (18.8%)
Prior HS surgeries (n, %)		
Any surgery	204 (22.8%)	147 (7.3%)

The incident biologic cohort comprised patients with HS, diagnosed prior to initiation of biologics, with first biologic prescription at selected dermatology clinics between January 01, 2016, and June 30, 2024. Index date is patient's first date of biologic initiation. The incident moderate/severe cohort comprised patients with first record of moderate/severe disease at selected dermatology clinics between January 01, 2016, and June 30, 2024. Index date is patient's first documented moderate/severe HS. Moderate/severe diagnosis is defined as Hurley stage II, Hurley stage III, or clinician-reported disease as moderate HS, or clinician-reported disease as severe HS, or starting a biologic treatment for HS. All percentages are calculated using non-missing data. Historical conditions prior to or at index date are not mutually exclusive. [a] Patients had body sites affected by HS however, the number and location of sites was not determined.

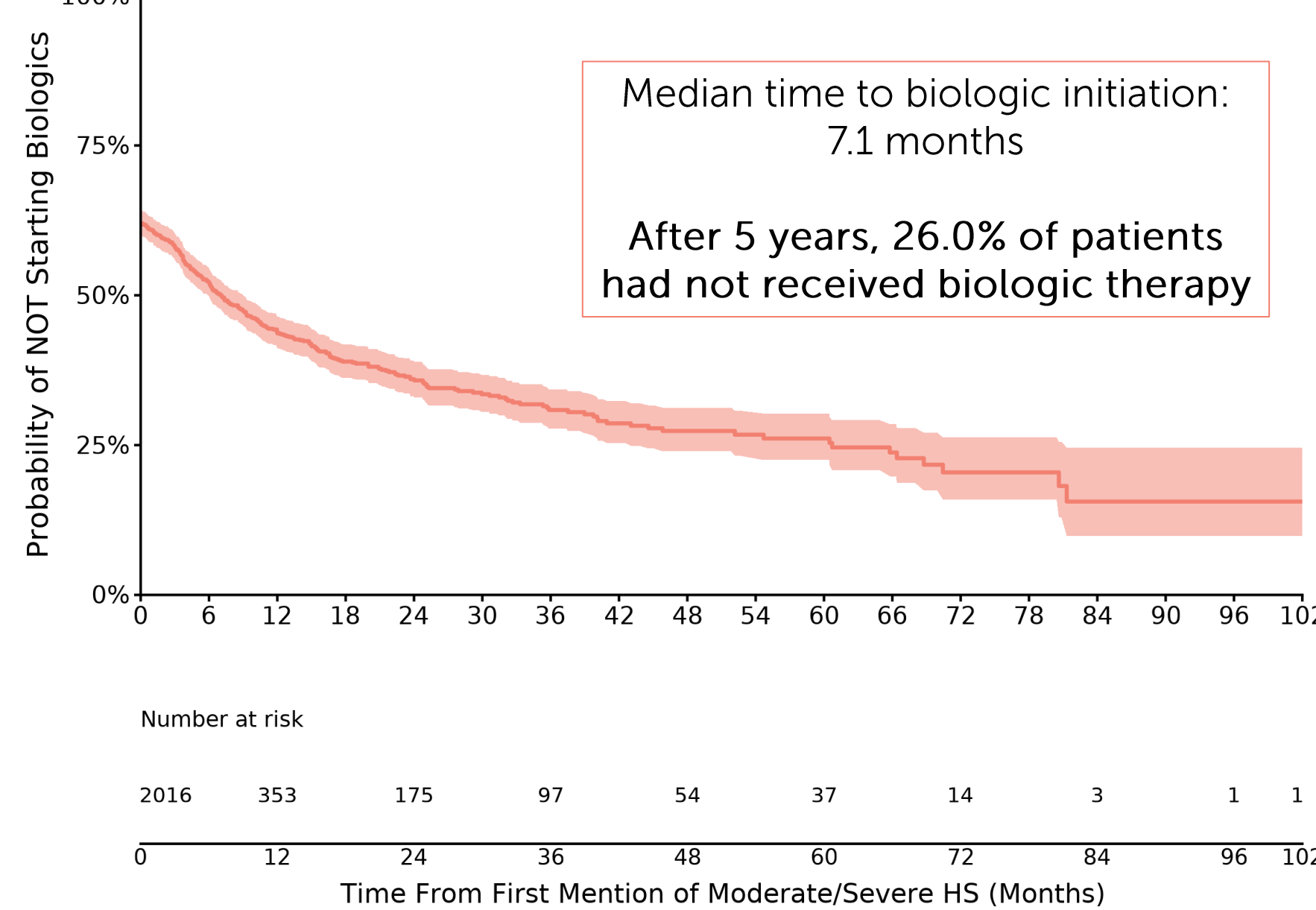
Figure 1



Affected body sites at index are not mutually exclusive. [a] Patients had body sites affected by HS however, the number and location of sites was not determined.

Figure 2

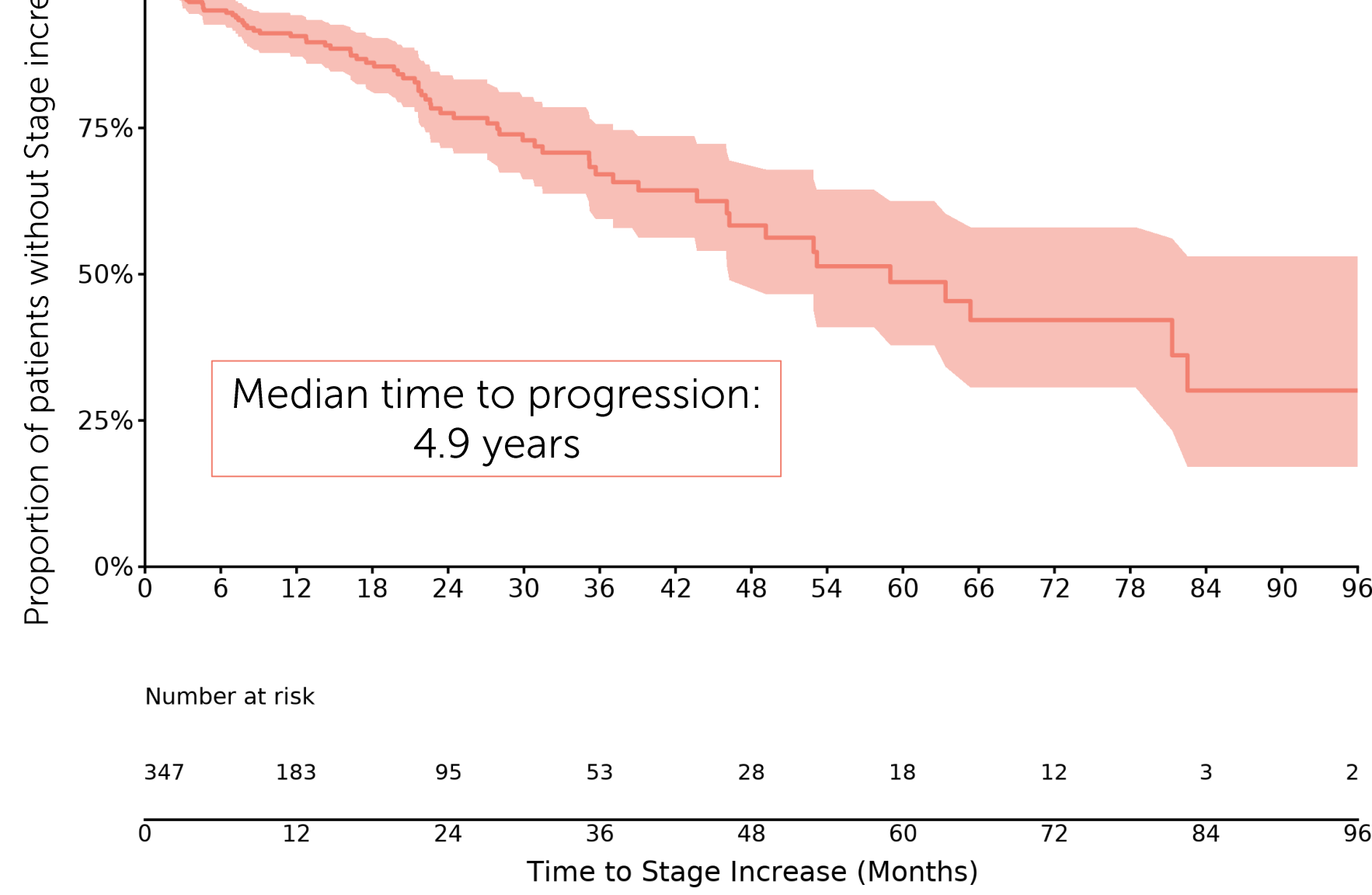
Time to starting biologics among incident moderate/severe cohort (N=2,016)



Time to starting biologics was measured in months from the date of moderate/severe HS until the date of starting any biologic treatment. Patients who do not start biologics were censored at their date of last follow-up. Note: The Kaplan-Meier curve begins at 62.1% because 37.9% had recorded initiation of biologic therapy on the same day as their incident moderate/severe HS diagnosis.

Figure 3

Time from Hurley stage II to Hurley stage III among moderate/severe cohort (N=347)



Defined as the time from first Hurley stage recorded in the note as II to the first record of a higher Hurley stage in moderate/severe patients. Clinician-reported severity was used as surrogate for Hurley stage in patients who do not have a reported Hurley stage. Mild = Hurley stage I, Moderate = Hurley stage II, and Severe = Hurley stage III. Analysis only includes patients with two or more recorded severity assessments. Patients were censored at the date of their last reported severity assessment.

EHRs: electronic health records; ETHiC: Epidemiology and Treatment of Hidradenitis Suppurativa in Canada; HS: hidradenitis suppurativa; IQR: interquartile range.

References: ¹Zouboulis CC et al. *Dermatology*. 2015;231:184–90. ²Matusiak L. *Br J Dermatol*. 2020;183:e171–77. ³Nguyen TV et al. *J Eur Acad Dermatol Venereol*. 2021;35:50–61. **Author Contributions:** MG, HL, IT, and RV contributed to the study conceptualization, data curation, funding acquisition, investigation, methodology, resources, software, supervision, validation, visualization, drafting of the original publication, and review and editing of the publication. DF, JF, DS, and PD contributed to the study conceptualization, data curation, funding acquisition, investigation, methodology, resources, supervision, validation, visualization, drafting of the original publication, and review and editing of the publication. **Author Disclosures:** MG: investigator, speaker, consultant or advisory board member for AbbVie, Acelyrin, Akros, Alumis, Amgen, AnaplysBio, Arcutis, Arista, Bausch Health, Boehringer Ingelheim, Bristol Myers Squibb, Dermavant, Dermira, Eli Lilly and Company, Galderma, GSK, Incyte, JAMP Pharma, Janssen, Kyowa Kirin, L'Oréal, MedImmune, Meiji, MoonLake Immunotherapeutics, Nektar Therapeutics, Nimbus, Novartis, Orluka, Pfizer, Q32 Bio, Regeneron, Reistone, Sanofi, Sun Pharma, Takeda, Tarsus, UCB, Union, Ventyx and Wyne. HL: Received consulting fees and/or acted as an advisory board member for AbbVie, Amgen, Aslam, AstraZeneca, Bausch Health, Bristol Myers Squibb, Celgene, Dermira, Eli Lilly and Company, Janssen, La Roche-Posay, LEO Pharma, MSD, MoonLake Immunotherapeutics, Novartis, Padiapharma, Pfizer, Regeneron and Sanofi; received grants/research support from LEADER Research; investigator in clinical trials for AbbVie, Amgen, Aslam, AstraZeneca, Bausch Health, Bristol Myers Squibb, Celgene, Dermira, Eli Lilly and Company, Janssen, La Roche-Posay, LEO Pharma, MSD, Novartis, Padiapharma, Pfizer, Regeneron and Sanofi. IT: Received honoraria and/or grants as a consultant, speaker, or investigator from AbbVie, Amgen, Apogee Therapeutics, Arcutis, Arista, Bausch Health, Bristol Myers Squibb, Boehringer Ingelheim, Eli Lilly and Company, Galderma, Horizon Therapeutics, Immagine Bio, Incyte, Janssen, Kiniksa, LEO Pharma, Mallinckrodt, MoonLake Immunotherapeutics, Novartis, Pfizer, Sanofi, Sun Pharma, Takeda, UCB and Ventyx Biosciences. DF, JF, DS, PD: Employees of UCB at the time of the study. RM, CP: Employees of Pentavere Research Group at the time of the study. RV: Received grants/research support from AbbVie, Amgen, Centocor, Dermavant, Dermira, Eli Lilly and Company, Galderma, GSK, LEO Pharma, Merck, Novartis, Pfizer, Regeneron, Takeda and UCB; speakers bureau/honoraria from AbbVie, Actelion, Amgen, Bausch Health, Celgene, CIPHER, Eli Lilly and Company, Galderma, GSK, Janssen, LEO Pharma, Merck, Novartis, Pfizer and UCB; received consulting fees from AbbVie, Actelion, Amgen, Bausch Health, Celgene, CIPHER, Eli Lilly and Company, Galderma, GSK, Janssen, LEO Pharma, Merck, Novartis, Palladin, Pfizer and UCB. **Acknowledgements:** The authors thank the patients, the investigators and their teams who took part in the study. The authors also thank Francis Grant, PhD, of UCB, for editorial review during poster development and publication coordination, and Michelle Nguyen, PhD, from Pentavere Research Group, Canada, for medical writing and editorial assistance based on the authors' input and direction. This study was funded by UCB. All costs associated with development of this presentation were funded by UCB.



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