

Barriers to Accessing Timely and Adequate Treatment, Care, and Resources for Patients with HS in Select US States

Steven Daveluy,¹ Brindley Brooks,² Brent Hazelett,³ Iltefat Hamzavi,⁴ Anne DiSalvo,⁵ Theresa Schmidt,⁵ Danuta Marchi,⁶ Laura McClung,⁷ Silky Beaty,⁷ Jasmine I. Espy,⁸ Stephanie Goldberg⁹

Objective

To evaluate state and district-level factors that influence care access and outcomes for patients with hidradenitis suppurativa (HS) in the United States (US).

Background

- HS is a chronic and debilitating inflammatory skin condition that causes acutely painful flares and impacts at least 0.1% of the US population.^{1,2}
- Patients with HS face late diagnosis, seven to nine years on average after symptom onset.³
- An independent HS Coalition was initiated to unify stakeholders such as patient-led organizations (including the Association of HS and Inflammatory Diseases [AHSID] and HS Connect), healthcare professionals (HCPs) and professional societies (including the HS-specific HS Foundation) to harness their collective expertise with the key objective to address health inequities in HS.

Methods

- A targeted literature review, environmental scan, and analysis of public and private datasets were conducted from November 2022–March 2023 for four states (California, Georgia, Louisiana, Michigan) and one district (Washington, District of Columbia [D.C.]) (Figure 1). Public and private datasets were also analyzed to generate insights at the national level, thereby contextualizing state/district-level findings.
- Real-world claims data from multiple payer channels were obtained from Real Chemistry's IPM.ai integrated claims private database.⁴
- Nationally, 151,651 distinct US patients with a code for HS included on ≥2 claims in the dataset, and at least one claim from December 2021–December 2022, were assessed.

Results

- Patients with HS are primarily covered by commercial insurers and Medicaid. Coverage varies between states and districts. In the four Medicaid expansion states reviewed here, a higher percentage of patients with HS were covered by Medicaid (e.g., Washington, D.C.: 64%), while Georgia, the one non-expansion state reviewed, had the lowest percentage of all states/district studied (26%) (Figure 2).
- Medicaid insurance policies vary between different states. Some have uniform preferred drug lists, requirements for prior authorization, and/or quantity limits for biologics (Table 1).
- Once diagnosed, many patients with HS qualify for disability benefits. However, initial denial rates of Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI) applications (across all applicants) are high, at 52–61%; reconsideration hearings have 14–20-month wait times with approval rates of 50–63% (Figure 3).^{5–8}
- Few HS-specific quality measures (tools to measure/quantify healthcare processes, outcomes, patient perceptions, and organizational structure/systems) were identified in select publicly-reported accountability programs (Table 2).

Conclusions

Depending on which state they live in, US-based patients with HS face different challenges to accessing care, given delay in diagnosis and restrictive insurance policies. These differences compound the existing health inequity in HS. A limitation of this study results from the size of the database, which may underestimate cases of HS. Fewer barriers to care are needed to improve patient clinical outcomes and quality of life. The new independent HS Coalition is formed in the US with a vision that "All people with HS have equitable access to care to achieve optimal outcomes."

Plain Language Summary

Why was this study needed?
To show how hard it can be for patients with hidradenitis suppurativa (HS) to get quality care quickly.

What did this study show?
The quality and speed of care patients with HS receive is impacted by their location. There are not many ways to measure the quality and speed of HS-specific care.

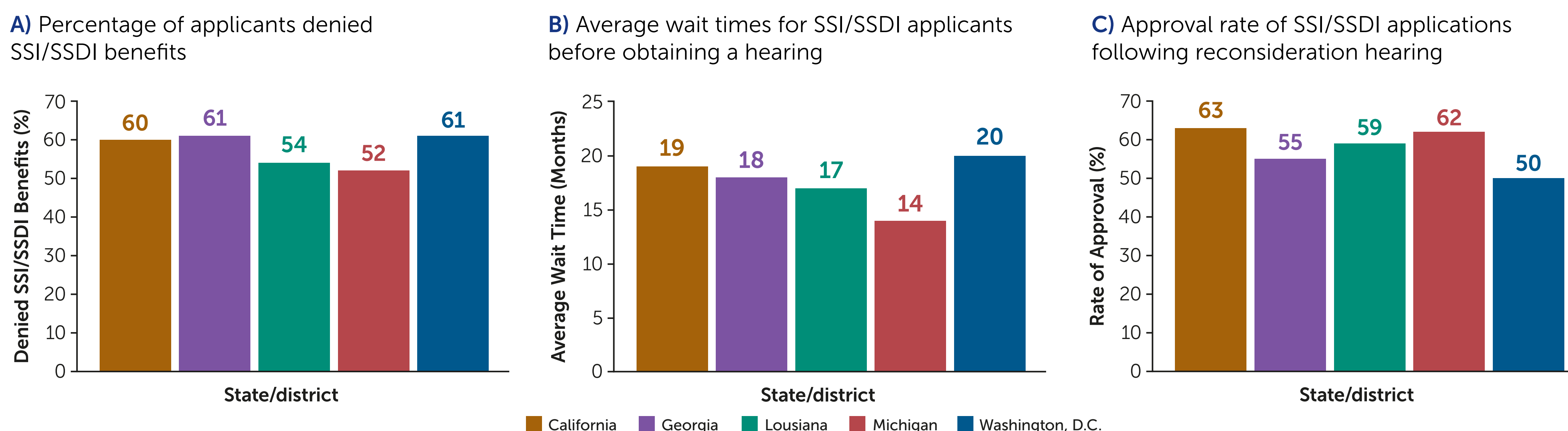
Why is this important?
The HS Coalition's goal is for all people with HS to have equitable access to care and to achieve optimal outcomes. We need to understand what barriers exist in order to find future solutions.

Table 1 Select Medicaid policies by state/district

	California	Georgia	Louisiana	Michigan	Washington, D.C.
Preferred Drug Lists (Uniformity)	Single PDL	Multiple PDLs	Single PDL	Single PDL	Multiple PDLs
Prior Authorization for Adalimumab*	Prior authorization is not required	Prior authorization is required	Prior authorization is required	Prior authorization is not required	Certain Medicaid MCOs require prior authorization
Quantity Limits for Biologics	Applies across all of Medicaid (single PDL)	Applies to FFS and 1 (of 3) MCOs	Applies across all of Medicaid (single PDL)	The use of adalimumab for HS is not specified within the MI PDL	Applies to 1 (of 3) MCOs

*At the time of these analyses, adalimumab (Humira) is the only FDA-approved prescription biologic indicated to treat moderate to severe HS.

Figure 3 Barriers to SSI/SSDI benefits



A) Percentage of applicants that have been denied SSI/SSDI benefits, denial rates between 2020 and 2023. B) Average wait time for SSI/SSDI applicants before obtaining a hearing at the hearing office (following rejection of their reconsideration request).⁵ C) Approval rate of the SSI/SSDI applications by an administrative law judge.^{7,8}

AHSID: Association of Hidradenitis Suppurativa and Inflammatory Diseases; CA: California; CAHPS: Consumer Assessment of Healthcare Providers and Systems; CHIP: Child Health Insurance Program; CMS: Centers for Medicare and Medicaid Services; D.C.: District of Columbia; FDA: Food and Drug Administration; FFS: fee-for-service; GA: Georgia; HCP: healthcare professional; HEDIS: Healthcare Effectiveness Data and Information Set; HS: hidradenitis suppurativa; LA: Louisiana; N/A: not applicable; MCO: managed care organization; MI: Michigan; MIPS: Merit-based Incentive Payment System; PDL: preferred drug list; PY: Performance Year; QCDR: Qualified Clinical Data Registry; QPP: Quality Payment Program; SSA: Social Security Administration; SSI: Supplemental Security Income; SSDI: Social Security Disability Insurance; US: United States.

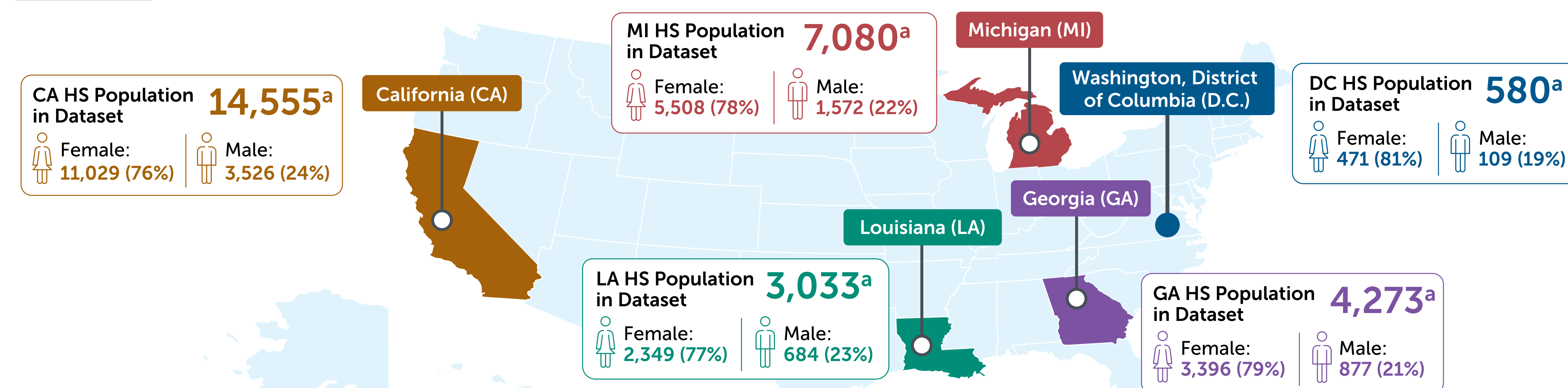
Institutions: ¹Department of Dermatology, Wayne State University School of Medicine, Detroit, MI, USA; ²HS Connect, Puyallup, WA, USA; ³HS Foundation Apex, NC, USA; ⁴Department of Dermatology, Henry Ford Hospital, Detroit, MI, USA; ⁵Real Chemistry, Washington, DC, USA; ⁶UCB Pharma, Brussels, Belgium; ⁷UCB Pharma, Smyrna, GA, USA; ⁸Association of Hidradenitis Suppurativa and Inflammatory Diseases (AHSID), Ypsilanti, MI, USA; ⁹Mary Washington Healthcare, Fredericksburg, VA, USA.

References: ¹Garg et al. JAMA Dermatol. 2017;153:760–64; ²Jfri et al. JAMA Dermatol. 2021;157:1–8; ³Hercules. Strategic health initiative to determine the standard of care for patients with Hidradenitis Suppurativa. 2017; ⁴IPM.ai. Integrated Claims (https://www.ipm.ai/). Accessed July 28, 2023; ⁵SSA. SSA State Agency Monthly Workload Data. https://www.ssa.gov/disability/data/ssa-sa-mowl.htm. Accessed February 13, 2023; ⁶SSA. Average Wait Time Until Hearing Held Report https://www.ssa.gov/appeals/DataSets/01_NetStat_Report.html. Accessed February 13, 2023; ⁷SSA. ALJ Disposition Data FY 2023. https://www.ssa.gov/appeals/DataSets/03_ALJ_Disposition_Data.html. Accessed February 13, 2023; ⁸SSA. Hearing Office Locator. https://www.ssa.gov/appeals/DataSets/01_NetStat_Report.html. Accessed February 13, 2023; ⁹QPP. Quality Payment Program Experience Report. https://data.cms.gov/quality-of-care/quality-payment-program-experience. Accessed January 23, 2023; ¹⁰CMS. 2020 Child and Adult Health Care Quality Measures Quality. https://data.medicare.gov/dataset/fbbe1734-b448-44e5a-b294-398689534741/data. Accessed January 23, 2023; ¹¹CMS. 2023 Medicare Advantage and Part D Star Ratings Fact Sheet. https://www.cms.gov/files/document/2023-medicare-star-ratings-fact-sheet.pdf. Accessed February 1, 2023. Author Contributions: Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: SD, BB, BH, IH, AD, TS, DM, LM, SB, JIE, and SG. Drafting of the publication, or reviewing it critically for important intellectual content: SD, BB, BH, IH, AD, TS, DM, LM, SB, JIE, and SG. Final approval of the publication: SD, BB, BH, IH, AD, TS, DM, LM, SB, JIE, and SG.

Author Disclosures: SD: Speaker for AbbVie and UCB Pharma; consultant for AbbVie, Novartis and UCB Pharma; research grants from AbbVie, Pfizer, and UCB Pharma. BB: Novartis, UCB Pharma, and Sanofi have provided previous payments to institution. UCB Pharma has provided previous payments to BB for lectures, presentations, speakers, bureaus, manuscript writing, and educational events. BH: None. IH: Consultant for AbbVie, Avita, Boehringer Ingelheim, Galderma, Incyte, Janssen, Novartis, Pfizer, Sonoma, UCB Pharma, and Union Therapeutics; investigator for Avita, Incyte, Lencic, L'Oréal/La Roche-Posay, and Pfizer; board member and past-president of the HS Foundation and Global Vitiligo Foundation. AD: Director, Market Access at Real Chemistry, under contract with UCB Pharma. TS: Vice President, Market Access at Real Chemistry, under contract with UCB Pharma. DM, LM: Employees and shareholders of UCB Pharma. SB: Employee of UCB Pharma at time of research, shareholder of UCB Pharma. JIE: UCB Corporate Sponsor, Consultant/ Speaker/Advocate for UCB Pharma, AbbVie, and Novartis; member of the Coalition for Skin Diseases and GlobalSkin; CEO/Executive Director of the Association of Hidradenitis Suppurativa and Inflammatory Diseases (AHSID). SG: Consultant for Novartis & UCB Pharma; Board Member of HS Foundation; member of HS Coalition.

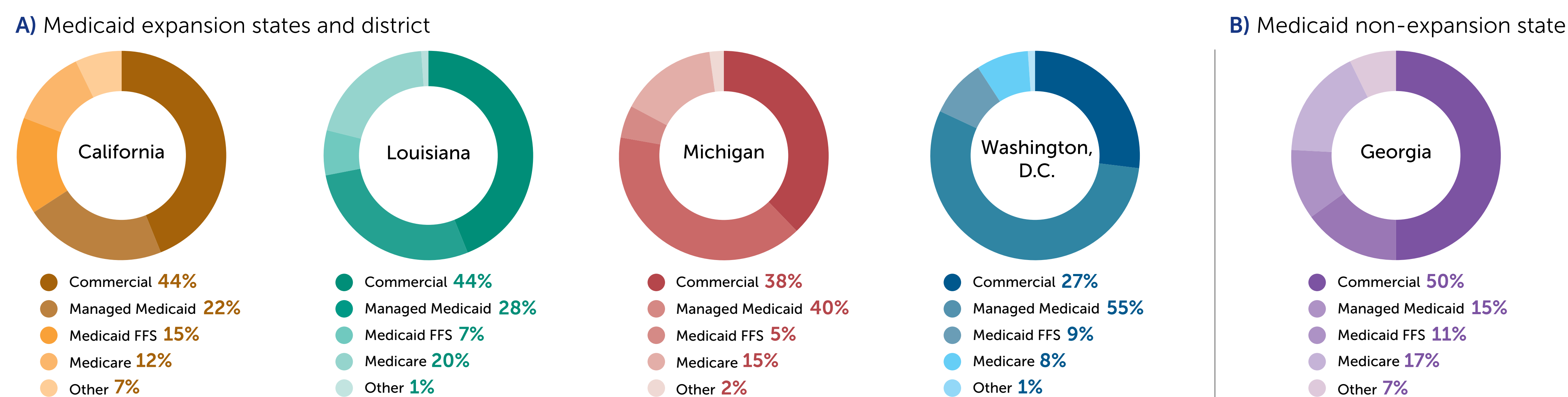
Acknowledgements: This study was conducted by Real Chemistry, with support and funding from UCB Pharma. The authors acknowledge Susanne Wiegatz, MSc, UCB Pharma, Monheim, Germany for publication coordination, Natasha Trujillo, UCB Pharma, GA, USA and Margaret Alabi, UCB Pharma, GA, Regeneron, NY, USA for project conception, Charlotte Marris, PhD, Costello Medical for medical writing and editorial assistance, and the Costello Medical Creative Team for design support. All costs associated with development of this poster were funded by UCB Pharma.

Figure 1 Map of US states/district selected for review



Four states and one district were included in the analysis dataset, with a similar ratio of male to female patients with HS. These areas were selected due to various criteria: high prevalence of patients with HS, high percentage of Black individuals, representation of provider advocacy efforts and/or HS programs in place, presence of HS specialty clinics, selection of states with and without Medicaid expansion, variation in average income level, and their dispersal across all regions of the US. ^aIncludes patients with a code for HS included on ≥2 claims, and at least one claim from December 2021–December 2022, extracted from the IPM.ai real-world claims dataset.

Figure 2 Distribution of patients with HS by payer type



States and district are grouped by the status of action of the Medicaid expansion decision. A) The states and district which have adopted and implemented Medicaid expansion. B) The state which has not adopted Medicaid expansion. "Other" includes the Health Insurance Marketplace, Child Health Insurance Program, workers compensation, cash, special needs, non-benefit (assistance programs, discount cards, patient assistance programs and vouchers), and coverage for the elderly (non-Medicare, Program of All-Inclusive Care for the Elderly). It does not include the null/unknown patients.

Table 2 Relevant measures in quality/payment programs

		National Average Performance	Measure set	Accountability Program
HS-specific	Chronic Skin Conditions: Patient-Reported Quality of Life	N/A ⁹	QCDR	QPP/MIPS
	Comprehensive Diabetes Care: Hemoglobin A1c Poor Control (>9.0%): Ages 18 to 75	42% ¹⁰ Medicaid PY 2020	HEDIS Medicaid Core Set	Medicaid Managed Care Medicare Part C & D Star Ratings QPP/MIPS
Chronic Condition Management	Screening for Depression and Follow-Up	7% ⁹ QPP/MIPS PY 2020	HEDIS Medicaid Core Set	Medicaid Managed Care QPP/MIPS
	Care for Older Adults – Pain Assessment (Special Needs Plans Only)	90% ¹¹ 2023 Star Ratings	HEDIS	Medicare Part C & D Star Ratings
Cross-cutting	CAHPS Health Plan Survey: Rating of Health Plan	87% ¹¹ 2023 Star Ratings	CAHPS	Medicare Part C & D Star Ratings Medicaid Managed Care

Federal, state, and private programs hold providers and payers accountable for care and outcomes. These measures can serve as levers to engage stakeholders and promote change. This list is not exhaustive. ⁹This QCDR measure is available for clinicians to report on as part of the QPP; but no reporting was made in performance year 2020.



To receive a copy of this poster, scan the QR code or visit: https://www.ssa.gov/appeals/DataSets/03_ALJ_Disposition_Data.html
UCBPharma.com/SHSA2023
Poster ID: 3000120
Link expiration: 29 October 2023