

Real world analysis of paid claims database reveals that disseminated superficial actinic porokeratosis (DSAP) is large orphan disease

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Synopsis

Disseminated superficial actinic porokeratosis (DSAP) is a serious chronic, progressive premalignant genodermatosis resulting from mutations in the mevalonate pathway that causes hyperkeratotic, pruritic, red or brown rings on sun-exposed areas such as the arms and legs, that can number in the hundreds leading to substantial discomfort, disfigurement, and psychosocial burden. DSAP can lead to malignant transformation including squamous cell carcinoma. There are no FDA-approved therapies for DSAP, and no effective treatment options. We characterized the diagnosed population of DSAP patients in the U.S.

Objective

We used the Komodo Health real-world paid claims platform to develop an algorithm to identify patients with probable DSAP using combinations of DSAP-specific diagnosis codes, related codes, and procedures through stepwise claims-based algorithms.

Results

After applying age-specific capture rates to the 8-year period, the total U.S. population is estimated to be 154,986 patients, and 78,950 patients were estimated with the more recent 3-year period (2023-2025).

Age distribution was strongly skewed toward older individuals: Patients aged 65-88 accounted for the vast majority (70% in 2023-2025; 61% in 2018-2025), with very few pediatric cases. Sex distribution: More females are seeking care compared to males (63% vs 36% in 2023-2025; 64% vs 35% in 2018-2025).

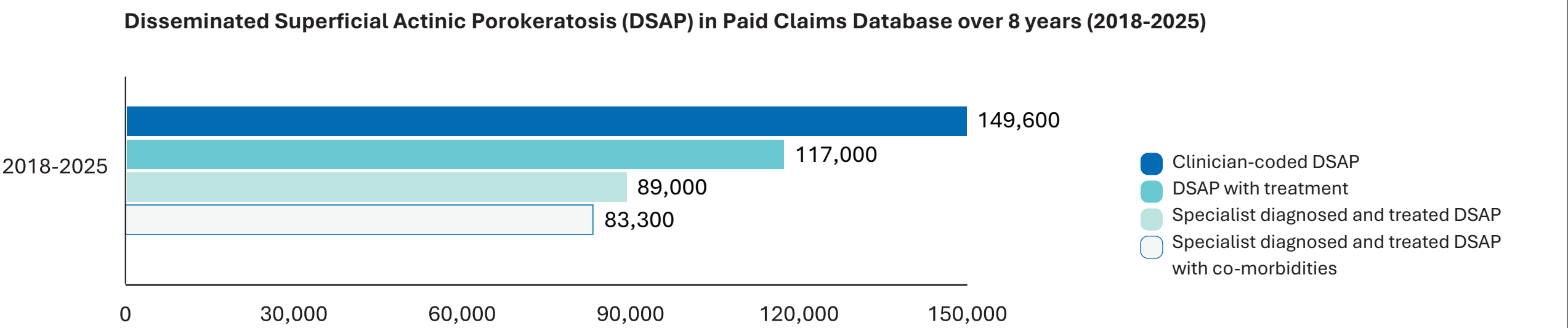


Table 1. Four claims-based algorithms were developed to identify individuals with DSAP.

Clinician-coded DSAP	2+ paid claim visits with ICD-10 diagnosis of L56.5 “Disseminated Superficial Actinic Porokeratosis”
DSAP with Treatment	2+ paid claim visits and receipt of off-label treatment for DSAP, e.g. diclofenac, fluorouracil, imiquimod, ingenol mebutate, tirbanibulin or treated with liquid nitrogen, cryotherapy
Specialist diagnosed and treated DSAP	2+ paid claim visits, off-label treatment, and visit with a specialist practitioner (dermatologist, nurse practitioner, or physician assistant)
Specialist diagnosed and treated DSAP with co-morbidities	2+ paid claim visits, off-label treatment, visit with a specialist practitioner, and comorbidities (actinic keratosis or cutaneous skin cancer diagnosis)

Analysis was done for each group using both an 8-year lookback (Jan 1 2018 - Dec 31 2025), as well as a 3-year lookback (Jan 1 2023 - Dec 31 2025)

Table 2. 94% of DSAP patients (83,300) who were specialist diagnosed and treated have comorbid actinic keratosis or skin cancer or both (2018-2025).

		DSAP and actinic keratosis		
		Yes	No	Total DSAP Patients
DSAP and skin cancer	Yes	45,300	1,000	46,300
	No	37,000	5,700	42,700
	Total DSAP Patients	82,300	6,700	89,000

Odds Ratio: 7.0 (95%CI: 6.5-7.5) p<0.0001, association with concomitant diagnosis of actinic keratosis and skin cancer (melanoma, squamous cell carcinoma, basal cell carcinoma, or Merkel cell carcinoma)

Table 3. After capture-rate adjustments, the estimated prevalence of diagnosed DSAP is 154,986.

Raw Claims (8yrs)	Age Groups	% Each Age	Raw Claims	Capture Rate Adjustment	Implied U.S. Population
149,600	25-44	3%	4,488	1.4	6,283
	45-64	32%	47,872	1.2	57,446
	65+	61%	91,256	1	91,256
					154,986

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Conclusion

The number of U.S. patients with DSAP is estimated to be 154,986 patients. This is the first study to characterize the diagnosed prevalence of the disease. 94% of DSAP patients who were specialist diagnosed and treated had actinic keratosis or skin cancer or both. Despite the lack of FDA-approved treatments, a large sub-set of individuals (up to 59%) were treated for DSAP with off-label topical immunomodulators or destruction therapy. Hence, there is currently a gap in the care of patients with DSAP and need for an FDA-approved treatment option.