

# Overall and Racial and Ethnic Subgroup Prevalence of Alopecia Totalis, Alopecia Universalis, and Ophiasis using the All of Us Database

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## INTRODUCTION

Alopecia areata is an immune-mediated disorder that targets hair follicles resulting in non-scarring hair loss. Severe subtypes include alopecia totalis (AT), alopecia universalis (AU), and ophiasis (O). AT is characterized by the loss of all scalp hair whereas AU manifests as loss of all body hair. [1] Ophiasis presents as a band-like area of alopecia extending across the occipital scalp only.[2] Currently, there is a lack of literature addressing the prevalence of these three rare alopecia areata subtypes in the U.S. The aim of our study was to estimate the prevalence of alopecia totalis, alopecia universalis, and ophiasis in the U.S. using the National Institute of Health's *All of Us* database, which provides health information on a diverse population.[3]

## METHODS

Cases of AT, AU, and O were identified using the International Classification of Diseases, Tenth Revision, Clinical Modification codes L63.0, L63.1, and L63.2 and SNOMED codes 86166000, 19754005, and 5860009, respectively. Prevalence was calculated using the Wald test with a 95% confidence interval (CI).

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## TABLES & FIGURES

Group	Total population, n (%)	Cases, n	Prevalence % (95% CI)	Female, n (%)
Overall	407,333	81	0.019885 (0.0002-0.0002)	63 (77.8)
Age group, y				
18-44	129,508 (31.8)	20	0.015445 (0.0001-0.0002)	14 (70.0)
45-64	151,436 (35.4)	30	0.019810 (0.0001-0.0003)	23 (76.7)
65+	133,831 (32.8)	31	0.023163 (0.0002-0.0003)	26 (83.9)
Racial/ethnic group				
Asian	14,162 (3.5)	2	0.014122 (0.0000-0.0006)	2 (100.0)
Black	73,321 (18.0)	18	0.001293 (0.0002-0.0004)	17 (94.4)
Hispanic/Latino	73,945 (18.1)	12	0.016228 (0.0001-0.0003)	9 (75.0)
White	226,615 (55.6)	44	0.019416 (0.0001-0.0003)	34 (77.3)

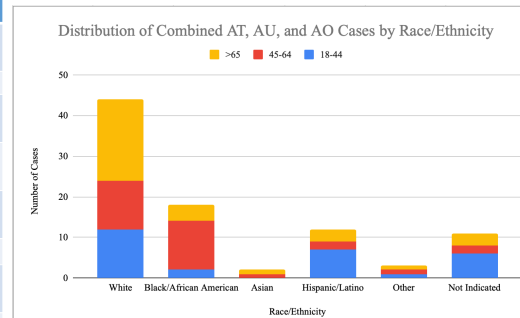


Table 1: Prevalence rates of patients with AT, AU, O based on gender, age, & race/ethnicity (left)  
Figure 1: Distribution of AT, AU, O cases by race/ethnicity and age group (above)

## RESULTS

Between 2018 and August 2023, the *All of Us* database had 407,333 participants. Prevalence for AT, AU, and O individually were 0.0096% (95% CI 0.0001-0.0001), 0.0088% (95% CI 0.0000-0.0000), and 0.0015% (95% CI 0.0001-0.0001), respectively. Together, there were 81 cases of AT, AU, and O (overall prevalence 0.0199%; 95% CI 0.0002-0.0002), 78% of which were female. When evaluated together, the mean ages of patients at diagnosis and current age were 51 years (SD 15.8) and 57 years (SD 15.3), respectively. These subtypes were most prevalent in ages 45-64 (0.0198%; 95% CI 0.0001-0.0003) (Figure 1). With respect to racial and ethnic groups, White patients had the highest prevalence (0.0194%; 95% CI 0.0001-0.0003), followed by Hispanic/Latino patients (0.01623%; 95% CI 0.0001-0.0003) (Table 1). All age groups and racial/ethnic groups had a female predominance (77% overall).

This analysis estimates that cases of AT, AU, and O combined affect 19.9 individuals out of every million people in the US. In 2019, Mostaghimi et al and Sy et al previously reported combined prevalence rates of AT and AU in the US of 0.019 and 0.010, respectively. [1,4] In comparison to our findings, a meta-analysis conducted by Lee et al. reported higher worldwide prevalence rates of AT (0.08%; 95% CI 0.04-0.13) and AU (0.03%; 95% CI 0.01-0.06), but similar prevalence rates for O (0.001%; 95% CI 0.001-0.057). [5]

## CONCLUSIONS

To our knowledge, this is the first large population-based study to estimate the combined prevalence of AT, AU, and O in the U.S. Limitations include reliance on EMR data and the patient pool from the *All of Us* database, which overrepresents older adults and underrepresents Asian individuals. Further population-based studies are needed to better understand the epidemiology of these rare alopecia subtypes.

## REFERENCES

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