

The Burden of Prader-Willi Syndrome on Patients and the Healthcare System: A Cross-sectional Examination of Emergency Department Visits and Inpatient Stays in U.S. Claims

Raj Gandhi¹, Mae Kwong¹, Michelle Guo², Rohan Bhutkar², and Mitch Nagao¹
¹Soleno Therapeutics, Redwood City, CA; ²Charles River Associates, New York, NY

INTRODUCTION

Prader-Willi syndrome (PWS) is a complex developmental genetic disorder defined by hyperphagia, a chronic and life-threatening condition, characterized by constant thoughts about consumption, and a pathological urge to consume non-food and food items that cannot be satisfied.^{1,2}

PWS is associated with shortened life span, with a median age at death of approximately 23 years.¹ Hyperphagia-related complications is a leading cause of death due to choking, gastrointestinal perforation, and accidents, and contributes to ~one third of all deaths and half of deaths in children, according to a U.S. cause-of-death PWS analysis.²

Though PWS’ health economic burden has been described previously,⁴ specific services driving that burden have not been documented.

This analysis examined the utilization of emergency department (ED) visits and inpatient (IP) stays to inform the burden of PWS on patients and healthcare systems.

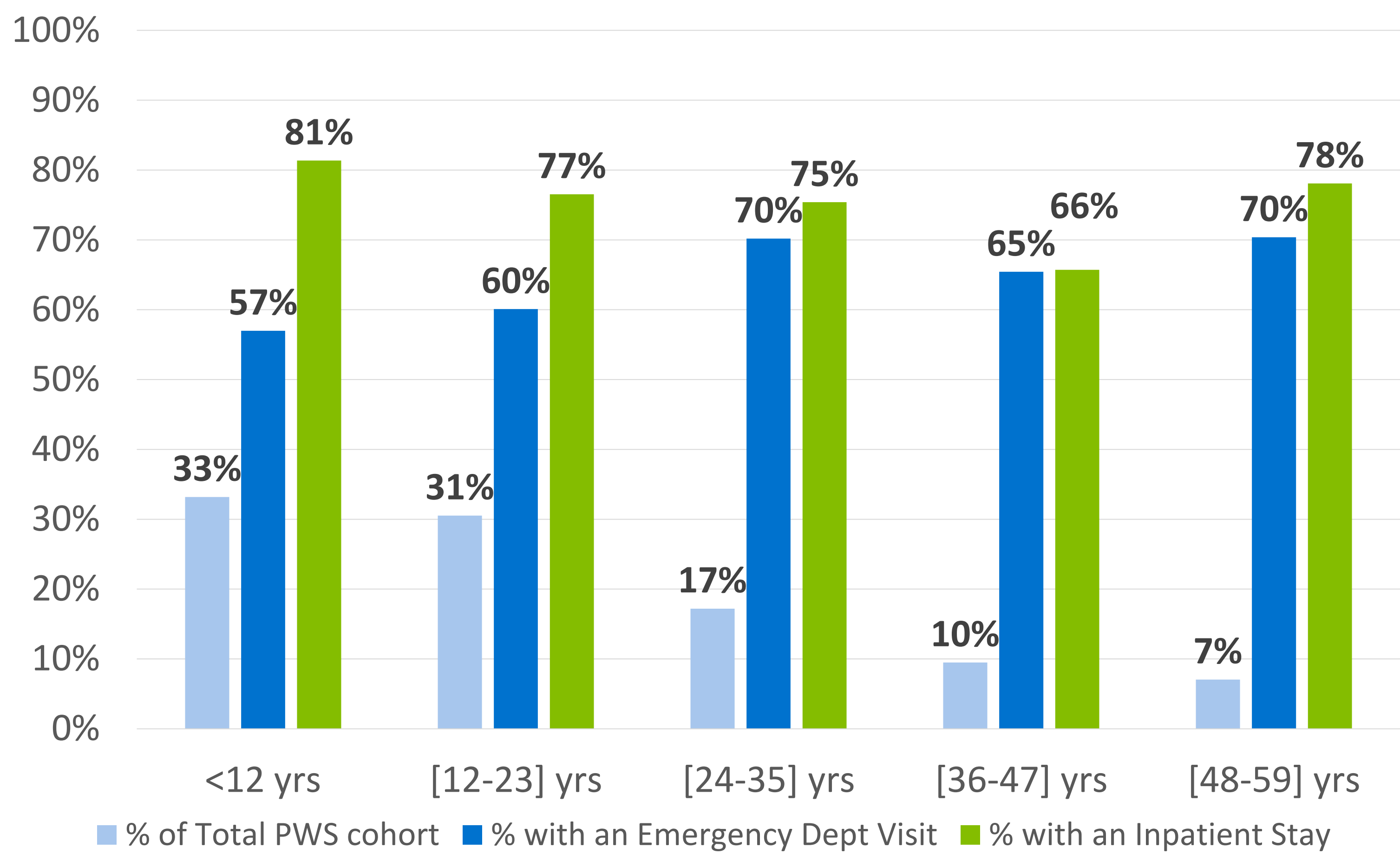
METHODS

- Observational retrospective analysis was performed on a de-identified U.S. closed-claims dataset (2021-2023).
- Patients with ≥2 claims with a diagnosis of PWS (Q87.11) >2 weeks apart were included in the analysis.
- Diagnoses and services codes occurring during this three-year period were documented with all utilization metrics annualized.
- Annual averages of ED visits and IP stays were stratified by age groups (<12, 12-23, 24-35, 36-47, 48–59 years).

RESULTS

- A total of 3,685 patients were included in the analysis.
- The proportion of patients with an **ED visit** increased up to the 24-35 age stratum and remained constant thereafter (**Figure 1**).
- The proportion of patients experiencing an annual **IP stay** is high for age strata and much higher than in the overall population (2019: 2.6% pediatric⁵).

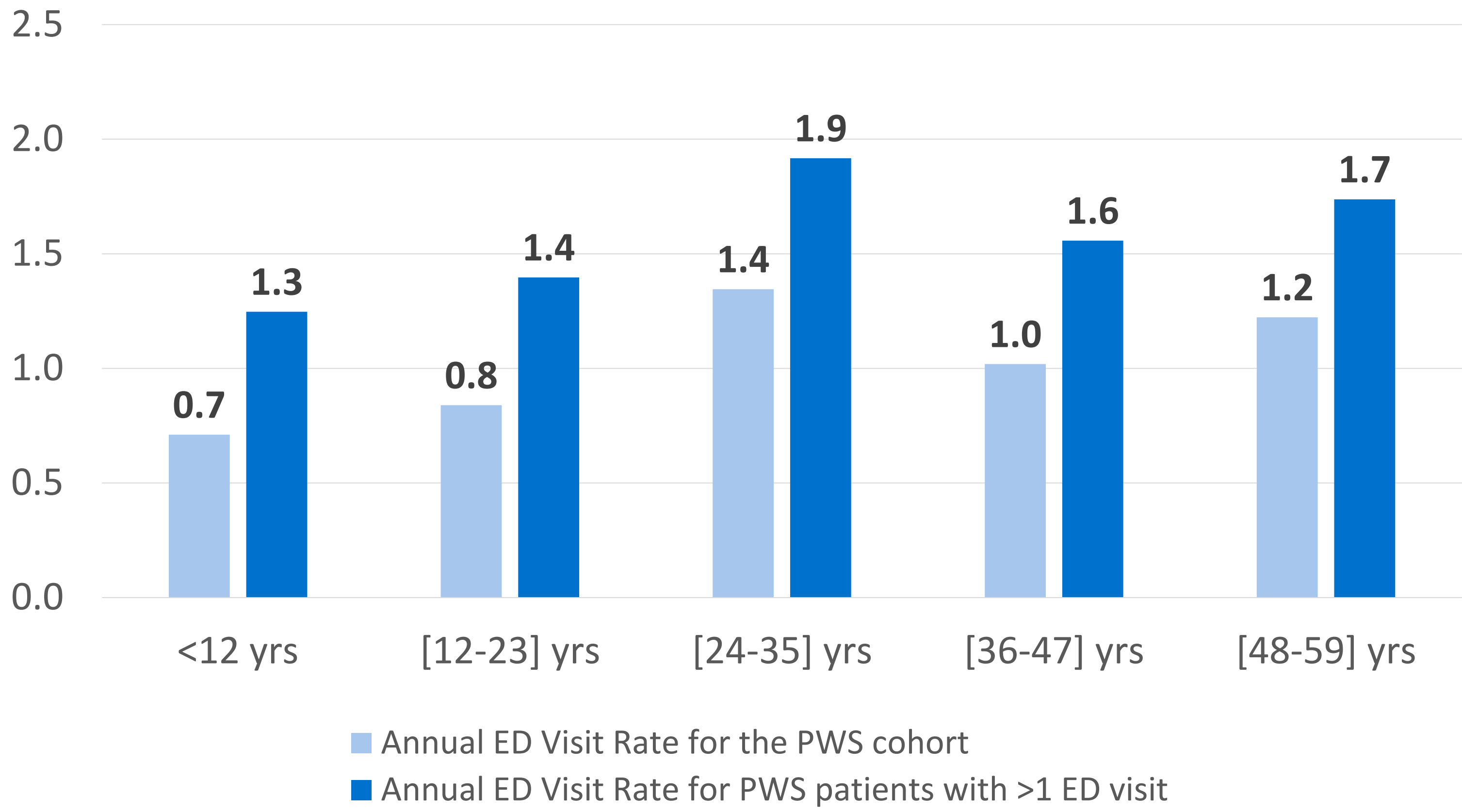
Figure 1. Percentage of PWS Patients with Services by Age Group



ED Visits

- The annual average rate of ED visits remained constant across all age strata.
- Older patients with at least one **ED visit** nearly averaged 2 visits/year, suggesting that some patients carry a greater disease burden than others (**Figure 2**).

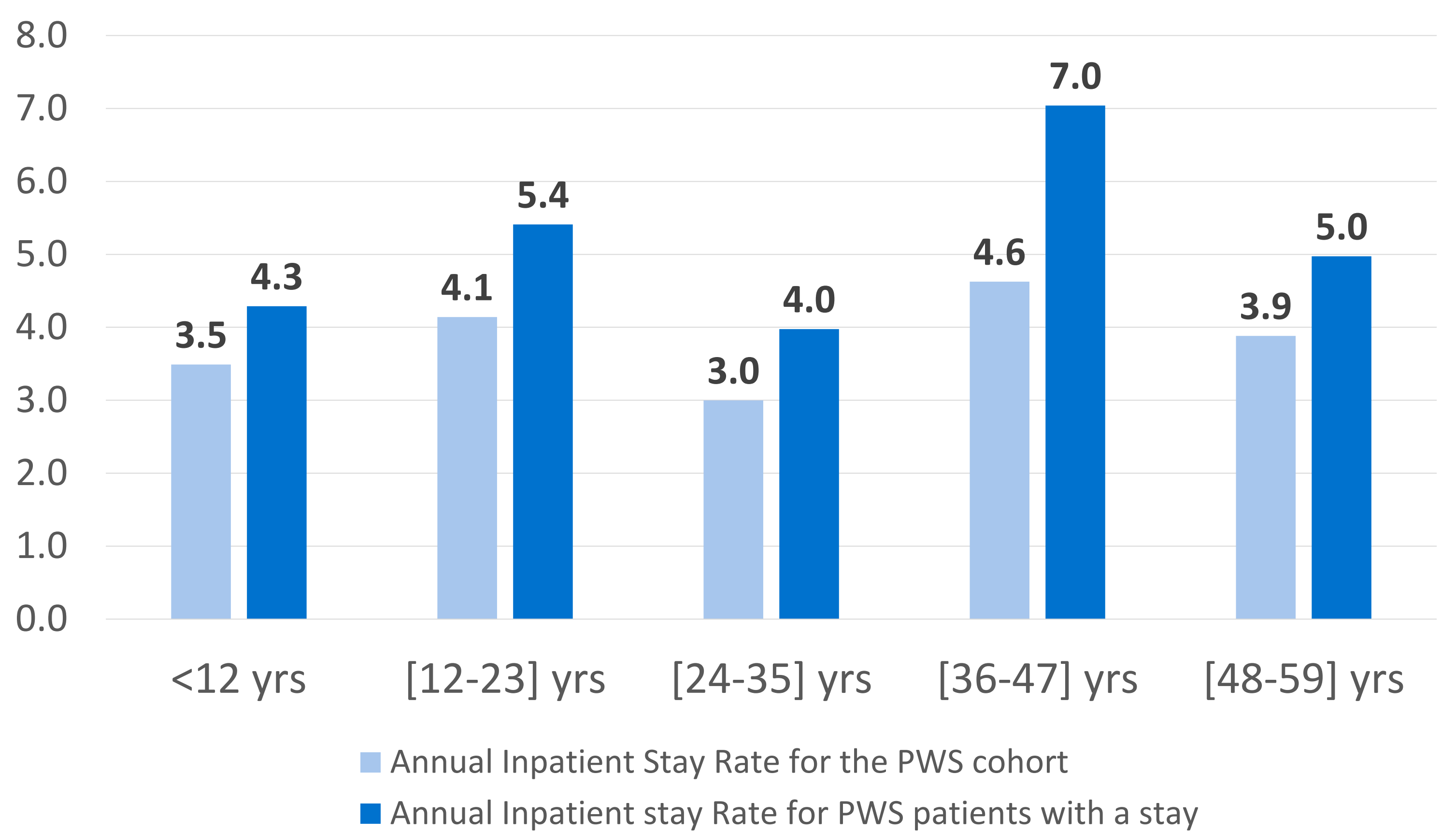
Figure 2. Annual Mean Number of ED Visits for PWS Patients by Age Group



Hospitalization

- Across all age strata, PWS patients averaged at least 3 **IP stays** per year.
- Patients with at least one **IP stay** tend to have a greater likelihood of rehospitalization, reinforcing that some patients carry a greater burden (**Figure 3**).

Figure 3. Annual Mean Number of IP Stays for PWS Patients by Age Group



CONCLUSIONS

- High utilization of ED and IP services was observed across all age groups, despite a declining population size as a function of age due to mortality.
- Utilization of ED and IP services was >4 times higher in pediatric PWS patients compared to the general pediatric population (2019 CDC data).
- These real-world analyses highlight the substantial burden of PWS on both patients/caregivers and the U.S. healthcare system, underscoring the considerable need for effective treatments for hyperphagia in PWS.

ACKNOWLEDGEMENTS

Authors would like to thank BeaRWEI Research for their analytic and editorial support. Soleno Therapeutics funded the study.

REFERENCES

- McCandless SE, et al. *J Endocr Soc.* 2020; 4(Suppl 1): SUN-604.
- Butler MG, et al. *Genet Med.* 2017; 19(6): 635-642.
- Driscoll DJ, et al. In: Adam MP, et al. eds. *GeneReviews*. University of Washington, Seattle; 2023.
- Shoffstall AJ, et al. *J Pediatr.* 2016;175:137-143.
- Centers for Disease Control Hospital Stays , accessed Apr 18, 2025: <https://www.cdc.gov/nchs/data/hsr/2020-2021/HospStay.pdf>

Abbreviations: PWS, Prader-Willi syndrome; ED, emergency department; IP, inpatient; Avg, average; Pt, patient; yrs, years.

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