# Optimizing Hemophilia A Patient Management: A Descriptive Analysis of Patient Demographics, Sites of Care, Treatment Strategies, and Social Determinants of Health

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## Background

- Hemophilia A incidence is the same regardless of race or ethnicity, however, Hemophilia A care inequities across different racial groups are well documented. [1]
- Research shows African American Hemophilia A patients have worse functional status than white patients across all age groups and regardless of inhibitor status.[2]
- The median age of death remained consistently 10 years lower for Black and Hispanic males in comparison to White males.[3]

## Objectives

- Identify the following information to help address health inequities when developing clinical disease program development, formulary strategies, site-of-care, and benefit design:
  - Characterize patient demographics, payer mix, and certain social determinants of health (SDOH) measures to inform clinical disease program development.
  - Identify prescribing patterns and how often patients change therapy to inform formulary management strategies.
  - Highlight key considerations to include when developing site-of-care policies and determining benefit design.

## Methods

- Used publicly available CDC Bleeding Disorders Community Counts program to assess patient demographics, sites of care, treatment strategies, and social determinants of health.[4] While data came from different sources, it was collected over the same time period.
- To assess if treatment options differed across different races and ethnicities, patients were separated into two subgroups (African American or White).
- In the scenario the total number of products in a category wasn't the same as the overall value, then the combined total of the individual products was used for calculations.
- Per Community Counts definition, aminocaproic acid and tranexamic acid were classified as antifibrinolytics. Hemlibra, gene therapy, fitusiran, and concizumab were classified as novel products.
- CDC's national HTC directory was referenced to find the number of HTCs at a state level.[5] World Population Review was used to find each state's population for 2024.[6] Since the number of hemophiliacs per state was provided as a range, the upper limit of the range was used to calculate the ratio of hemophilia patients per state population.

## Results

Figure 1. Socio-Demographic Characteristics Based on HTC Registry

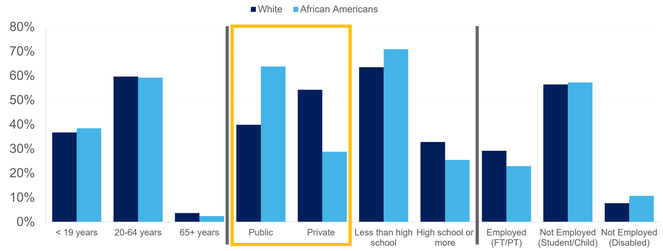


Figure 2. Current Treatment Regimen Based on HTC Registry

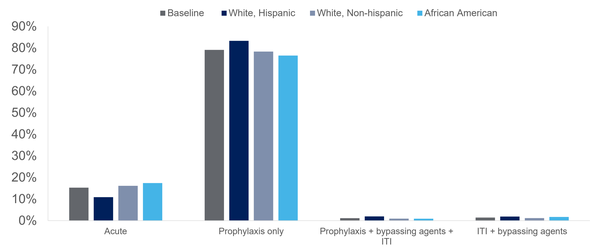


Figure 4a. Distribution of Patients and HTCs

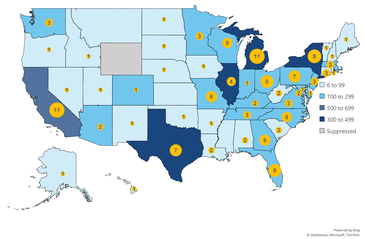


Figure 4b. Distribution of White Non-Hispanic and HTCs

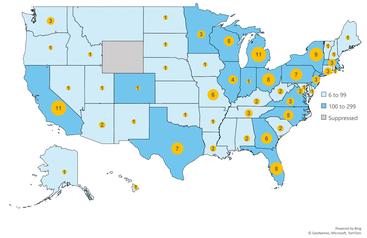


Figure 4b. Distribution of White Hispanic and HTCs

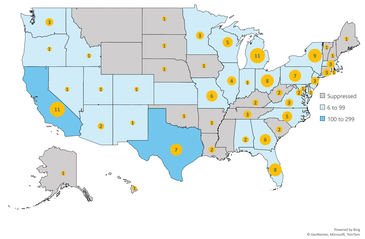


Figure 4d. Distribution of African American and HTCs

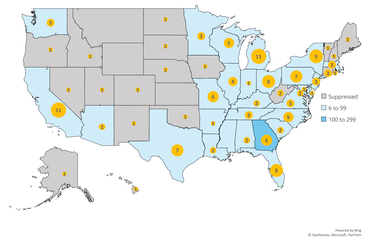


Table 1. Treatment: Patient Ratio Breakdown Per Race

| Patient Breakdown | Baseline | White Hispanic | White Non-Hispanic | African American |
|---|---|---|---|---|
| Total of Patients | 6,720 | 1,012 | 3,983 | 994 |
| Patients with No Treatment | suppressed | 36 | suppressed | suppressed |
| Total Number of Patients on Treatment | 6,720 | 976 | 3,983 | 994 |

| Product Type | Baseline | White Hispanic | White Non-Hispanic | African American |
|---|---|---|---|---|
| Clotting Factor | 5,799 | 844 | 3,523 | 832 |
| Antifibrinolytics | 762 | 115 | 416 | 126 |
| Other | 1,270 | suppressed | 641 | 215 |
| Total | 7,831 | 959 | 4,580 | 1,173 |

| Treatment: Patient Ratio | Baseline | White Hispanic | White Non-Hispanic | African American |
|---|---|---|---|---|
| | 1.17 | 0.95 | 1.15 | 1.18 |

## Conclusion

### Socio-economic Characteristics

Age, education level, and employment status are very similar across white and African American patients. However, most African American patients receive care under public insurance while White patients receive care under private insurance.

### Prescribing Patterns

There are no major differences in prescribing patterns across different racial groups regardless if patient is seeking care at the HTC Registry or HTC Patient Profile perspective.

### Sites of Care/Benefit Design

Some states do not have access to the same number of HTCs for patients to seek care. White-non-Hispanic patients are more dispersed to states with fewer HTCs whereas White-Hispanic patients are more dispersed to states with more HTCs. This highlights the inequities in access to HTC care.

## Limitations

- The conclusions are based on a population-level analysis limiting the ability to perform a more granular evaluation.
- CDC data comes from patients who opt-in to the hemophilia registry and those who seek care at HTCs. There is potential for data skew as the registry and HTCPP won't encompass all hemophilia A patients.

## Next Steps

- Isolate patients from non-Medicaid expanded states and compare clinical outcomes (such as bleeds and ER visits) and annual cost of care against comparable patients seeking care in Medicaid-expanded states.
- Analyze patients with Medicaid, Medicare, and private coverage and assess if there is a correlation between the level of coverage and being on certain treatment regimens.
- Assess how patient out-of-pocket costs may influence treatment selection.
- Find how far a patient is from the nearest HTC or hematology specialist and analyze if that impact a patient being on either prophylaxis or acute therapy.

## Acknowledgments

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## References

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