

# A Descriptive Survey of Patient Experiences with Alternative Funding Programs Among Patients with Bleeding Disorders and by Income Level

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LEP1

## INTRODUCTION & OBJECTIVE

- Alternative funding programs (AFPs) attempt to lower plan sponsor costs by excluding specialty medicines.
- Patients are then directed to obtain those medicines in other ways (typically, manufacturer patient assistance programs [PAPs]) via a third-party (i.e., AFP vendor).
- Several concerns have been raised around AFP programs including:
  - Ethical considerations of diverting limited resources from PAPs and charitable foundations (i.e., from patients who do not have insurance to patients who are otherwise insured).
  - Potential for treatment delays and disruptions.<sup>1,2,3</sup>
  - Additional administrative complexity for patients to obtain their medication, resulting in a negative experience for plan beneficiaries.<sup>1</sup>
- Patient experiences with AFPs, specifically among patients with hemophilia and other bleeding disorders (H/BDs) and separately, among patients with differing income levels, are unknown.

**The objective of this study was to describe patients' experiences with AFPs, stratified by patients with hemophilia and other bleeding disorders, and by annual income.**

<sup>1</sup> Alternative funding: Real savings, or real problems? Accessed March 27, 2024. <https://www.optum.com/business/insights/pharmacy-care-services/page.hub.alternative-funding-savings-problems.html>  
<sup>2</sup> Zuckerman AD, Schneider MP, Dusetzina SB. Health Insurer Strategies to Reduce Specialty Drug Spending-Copayment Adjustment and Alternative Funding Programs. JAMA Intern Med. 2023;183(7):635-636. doi:10.1001/jamainternmed.2023.1829  
<sup>3</sup> Avalere wp. Alternative Funding Programs Present Stakeholder Challenges. Avalere. Published June 12, 2023. Accessed March 27, 2024. <https://avalere.com/insights/alternative-funding-programs-present-stakeholder-challenges>

## METHODS

- 26-item online survey** consisting of optional single- and multiple-choice questions with branching logic was administered between Oct-Dec 2023 to patients in the United States who reported experience with AFPs. Patients were recruited concurrently online from Rare Patient Voice patient panels and the Hope for Hemophilia (HOPE) patient advocacy group. Only patients eligible based on a 4-item screener were invited to complete the survey.

## Broadly, the survey evaluated patients':

- awareness of AFPs
- experience with the PAP application process via the AFP vendor
- timeliness of medication access if granted and/or the health impact from a delay in medication access

Patient responses were categorized separately by:

- Disease area for which the specialty medicine was needed: (H/BDs, all other conditions,\* not reported) and annual income: <\$50k,>\$50k, not reported.
- A comparative analysis examined the impact of AFPs among patients with H/BDs compared to other diseases and among patients in each income group.
- Responses were analyzed descriptively (proportions, means) and reported only for patients who responded to the question(s).
- Respondents received compensation for their participation. The survey was administered via Qualtrics.

\*arthritis, skin conditions (such as psoriasis or eczema), Crohn's disease, ulcerative colitis, or other gastrointestinal disease, history of transplant, hepatitis, HIV/AIDS, and other rare diseases

## RESULTS

### Overall Sample

- A total of 7,546 patients completed the screener.
- 227 patients were included in the final sample (i.e., identified as having employer- or union-sponsored insurance, a chronic condition treated with specialty medication excluded from coverage [not due to step therapy], had contact with the AFP vendor to help enroll in free drug program, provided consent, and answered at least 1 survey question).
- Of the 227 patients, 211 reported their income or disease (30 patients with H/BDs, 175 with other conditions and 57 with income <\$50k, 129 with income >\$50k) (Table 1).

**Table 1. Survey Sample Demographics, by Disease Area and Income**

Patient Characteristics n (%)	All <sup>a</sup>	Disease Area			Income		
		H/BD	All other conditions <sup>b</sup>	Not reported	<50k	>50k	Not reported
<b>Total</b>	211 (100.0)	30 (14.2)	175 (82.9)	6 (2.8)	57 (27.0)	129 (61.1)	25 (11.8)
<b>Age</b>							
<b>Total</b>	211 (100.0)	30	175	6	57	129	25
≤34	82 (38.9)	17 (56.6)	61 (34.8)	4 (66.7)	29 (50.9)	41 (31.6)	12 (48.0)
35-44	46 (21.8)	9 (30.0)	36 (20.6)	1 (16.7)	7 (12.3)	36 (27.9)	3 (12.0)
45-54	50 (23.7)	3 (10.0)	47 (26.9)	0 (0.0)	14 (24.6)	35 (27.1)	1 (4.0)
55+	32 (15.2)	1 (3.3)	30 (17.2)	1 (16.7)	7 (12.3)	17 (13.2)	8 (32.0)
<b>Do not wish to report</b>	1 (0.5)	0 (0.0)	1 (0.6)	0 (0.0)	0 (0.0)	0 (0.0)	1 (4.0)
<b>Gender</b>							
<b>Total</b>	207 (100.0)	30	171	6	57	125	25
Female	61 (29.5)	20 (66.7)	37 (21.6)	4 (66.7)	18 (31.6)	35 (28.0)	8 (32.0)
Male	144 (69.6)	9 (30.0)	133 (77.8)	2 (33.3)	38 (66.7)	90 (72.0)	16 (64.0)
<b>Do not wish to report</b>	2 (1.0)	1 (3.3)	1 (0.6)	0 (0.0)	1 (1.8)	0 (0.0)	1 (4.0)
<b>Race and Ethnicity</b>							
<b>Total</b>	211 (100.0)	30	175	6	57	129	25
White, not Hispanic, Latino, or Spanish origin	150 (71.1)	12 (40.0)	137 (78.3)	1 (16.7)	32 (56.1)	102 (79.1)	16 (64.0)
Black, not Hispanic, Latino, or Spanish origin	18 (8.5)	6 (20.0)	12 (6.9)	0 (0.0)	12 (21.1)	4 (3.1)	2 (8.0)
Asian/Pacific Islander/American Indian or Alaska Native, not Hispanic, Latino, or Spanish origin	5 (2.4)	2 (6.7)	3 (1.7)	0 (0.0)	2 (3.6)	2 (1.6)	2 (1.6)
Hispanic, Latino or Spanish origin of any race	22 (10.4)	5 (16.7)	15 (8.6)	2 (33.3)	6 (10.5)	13 (10.1)	3 (12.0)
Two or more races and not Hispanic, Latino, or Spanish origin	4 (1.9)	0 (0.0)	4 (2.3)	0 (0.0)	2 (3.5)	2 (1.6)	0 (0.0)
<b>Race/ethnicity not listed or do not wish to report</b>	12 (5.7)	5 (16.7)	4 (2.3)	3 (50.0)	3 (5.3)	6 (4.7)	3 (12.0)

H/BD: Hemophilia or other bleeding or blood disorder

"Do not wish to report" represents participants who selected the response choice "do not wish to report." "Not reported" represents the total number of participants who skipped either the disease area or income question.

<sup>a</sup> Due to rounding, percentages may not add up to 100%.

<sup>b</sup> Includes arthritis, skin conditions (such as psoriasis or eczema), Crohn's disease, ulcerative colitis, or other gastrointestinal disease, history of transplant, hepatitis, HIV/AIDS, and other rare diseases.

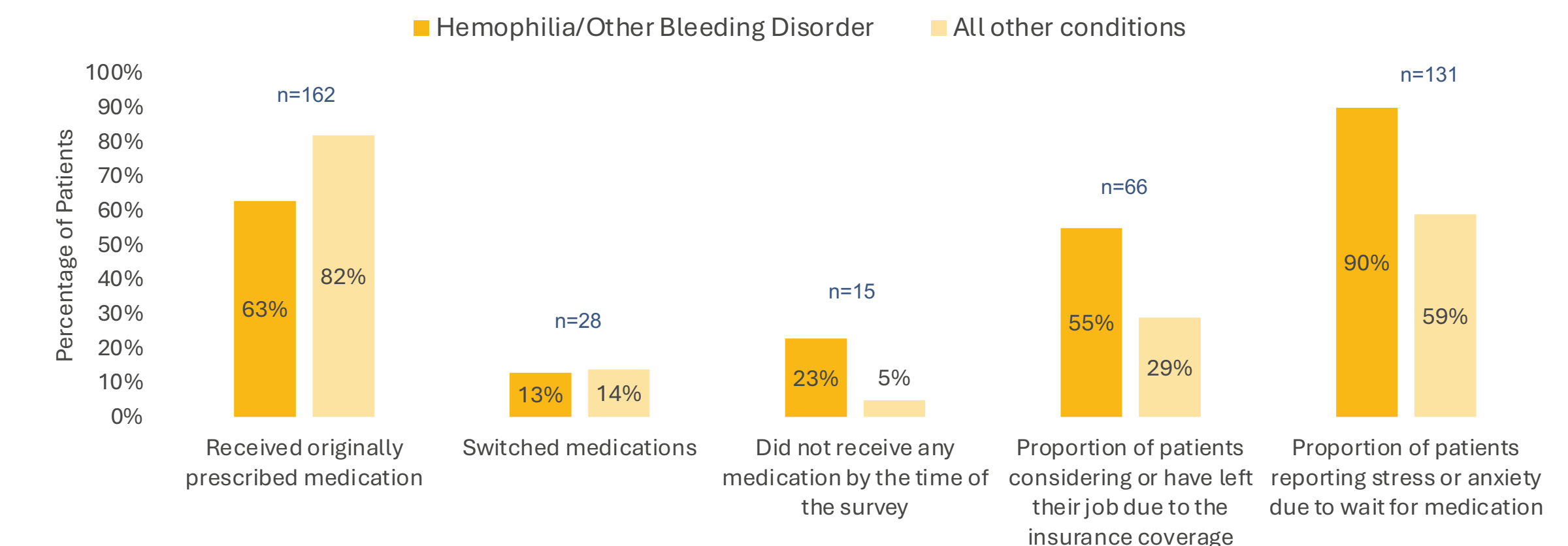
### Hemophilia/Other Bleeding Disorders versus Other Conditions

- Compared to patients with other conditions, fewer patients with H/BDs:
  - received their originally excluded medicine (63% vs. 82%) (Figure 1a)
  - had their initial PAP application approved (26% vs. 67%)
- Nearly all patients with H/BDs (90%) reported stress or anxiety due to the wait for medication, compared to 59% of patients with other diseases (Figure 1a)
- The mean wait time for patients with H/BDs to receive their medication was 83.7 days vs. 65.7 days for the overall sample (Figure 2).

### Income Level

- Compared to patients with an annual income >\$50k, a higher proportion of patients with an annual income of <\$50k did not receive any medication by the time of the survey (12% vs. 5%) (Figure 1b).
- More patients with an annual income of <\$50k considered leaving or left their jobs due to their insurance coverage than those in the >\$50k income group (43% vs. 32%) (Figure 1b).
- More than half of patients in both the <\$50k and >\$50k cohorts reported feeling stress or anxiety due to the wait for medication (61% and 64%, respectively).
- More patients in the <\$50k cohort (35%) than the >\$50k cohort (22%) reported their condition worsened due to the wait for medication.
- Patients with an annual income of <\$50k had a longer mean wait time for their medication (81.0 days vs. 67.7 days) (Figure 2).

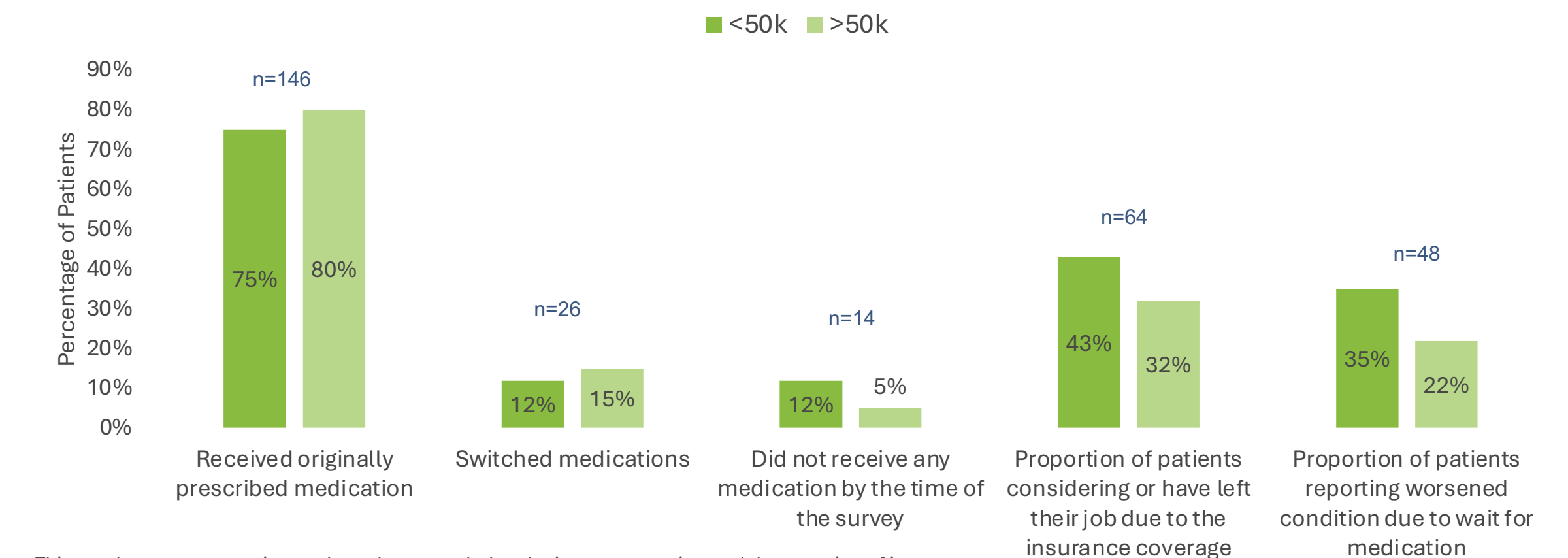
**Figure 1a. Receipt of Originally Prescribed Medication and Impact of AFP, by Disease Area**



This graph represents patients who only responded to the disease area question and the question of interest.

Not included in this graph is the total number of "Not Reported" (n=6). "Not reported" represents the total number of participants who skipped either the disease area or question or other questions of interest on this graph.

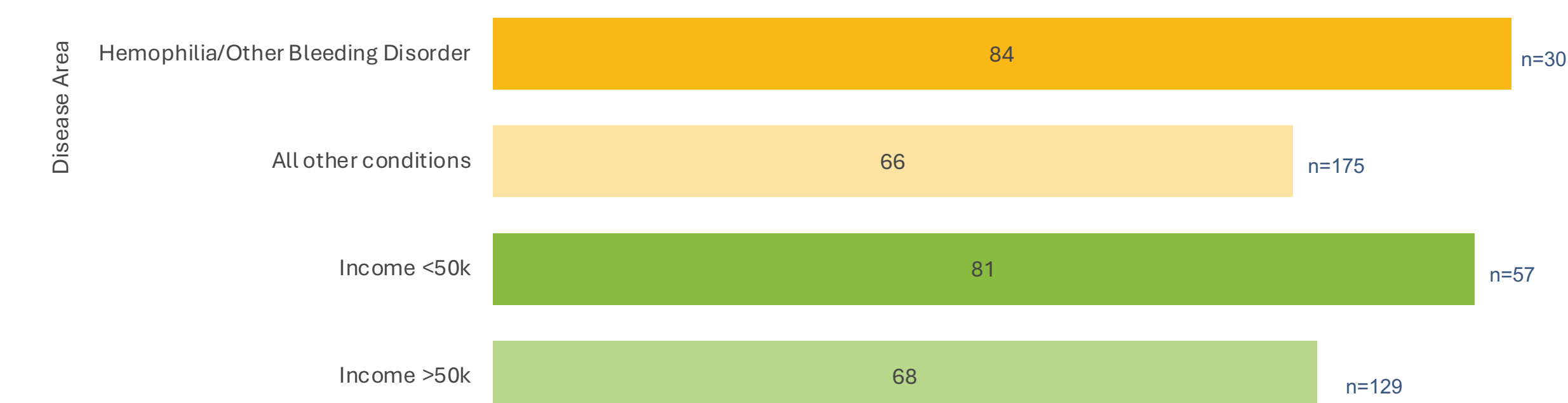
**Figure 1b. Receipt of Originally Prescribed Medication and Impact of AFP, by Annual Income**



This graph represents patients who only responded to the income question and the question of interest.

Not included in this graph is the total number of "Not Reported" (n=25). "Not reported" represents the total number of participants who skipped either the disease area question or other question of interest on this graph.

**Figure 2. Average Wait Time for Medication (days), by Disease Area and Income**



Not included in this graph is the total number of "Not Reported" (n=29). "Not reported" represents the total number of participants who skipped either the disease area or income question.

## KEY TAKEAWAYS

- While patients accessing their medicines through AFPs have longer than typical wait times for their medicines, patients with H/BDs and those with a lower annual income may especially have worse experiences and more challenges accessing their medication.**
- Employers should consider if AFPs may lead to disparities in medication access among their employees. Further research is warranted to explore any potential discriminatory effect of AFPs.