# A descriptive survey of patient experiences and access to specialty medicines with alternative funding programs

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## Plain language summary

Patients who have used alternative funding programs (AFPs) to access their medication were surveyed to understand their experiences. We found that using AFPs may lead to delays in patients receiving their medication, which may lead to worsening of their disease and add to their stress/ anxiety. Employers should be mindful that, because of AFPs, patients reported considering leaving their jobs to find a role with better insurance coverage.

## Implications for managed care pharmacy

AFPs may potentially disrupt patient access to specialty medications and be associated with a negative member experience. Further research is needed to understand the longerterm impacts on patients and health plan sponsors.

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## ABSTRACT

**BACKGROUND:** Alternative funding programs (AFPs) seek to reduce health plan sponsor costs, for example by excluding specialty drugs from a beneficiary's plan coverage and requiring patients to obtain medications through alternative sources (typically, the manufacturer's patient assistance programs) via an AFP vendor as a third-party.

**OBJECTIVE:** To describe patients' experiences and specialty medication access with AFPs.

**METHODS:** A survey method consisting of 26 optional single-choice and multiple-choice questions with branching logic divided across 5 sections (related to patient challenges with AFPs) was administered to patients recruited from an experienced AFP online patient panel and a patient advocacy group. The survey assessed patients' awareness of AFPs from their employers, experience with the patient assistance program application process via the AFP vendor, timeliness of medication access (if granted), and/or the health impact of delay in access. All descriptive and exploratory subgroup analyses were conducted by disease area and reported income levels; statistical analyses were carried out for the exploratory analyses.

**RESULTS:** The final sample included 227 patients. Most patients (61% [136/223]) first heard of the AFP as part of their health benefit when trying to obtain their medication. Of 198 patients, 88% reported being

stressed because of the medication coverage denial and the uncertainty of obtaining their medication. More than half of patients (54% [115/213]) reported being uncomfortable with the benefits manager from the AFP vendor. On average, patients reported waiting to receive their medication for 68.2 days (approximately 2 months); 24% (51/215) reported the wait for the medication worsened their condition and 64% (138/215) reported the wait led to stress and/or anxiety. Patients who indicated the wait time negatively affected them had considered a job change or left their job at a 3–5-fold higher rate than those who reported no impact from wait time. A significantly higher proportion of patients with hemophilia and other bleeding disorders reported receiving their prescribed medication less often than patients with other conditions (63% [19/30] vs 81% [52/64]; P=0.022), whereas more patients with lower incomes (<\$50,000 vs >\$50,000) reported not receiving any medication (12% [7/57] vs 5% [7/129]; P=0.657), although these differences were not significant.

**CONCLUSIONS:** Most patients who obtain their specialty medicines via AFPs reported being uncomfortable with the process and experiencing treatment delays, which may have been linked to disease progression, worsened mental well-being, and consideration of a job change. Employers should be aware of the potential downstream impacts on employee health, retention, and the employee–employer relationship when considering implementing an AFP into their health plan. Specialty medications have traditionally been defined as those that treat chronic, complex, or serious conditions.<sup>1</sup> Although many of these medications improve clinical outcomes, concerns have arisen about their affordability. Consequently, pharmaceutical manufacturers may offer copay assistance to improve affordability and reduce the out-of-pocket cost burden for commercially insured patients.<sup>2</sup> Alternatively, patient assistance programs (PAPs; free drug programs) or charitable foundations, which can be funded by manufacturers or other private sources, are aimed at supporting patients who are uninsured or underinsured (insured patients with significant financial burden).<sup>3,4</sup> Although PAPs and charitable foundations generally provide medications free of charge, income restrictions are typically in place, and patients with higher incomes are usually excluded from these programs.

In recent years, alternative funding programs (AFPs) have emerged as a new way to limit plan sponsors' exposure (ie, employers) to the cost of specialty medications. These programs are operated by vendors who work on behalf of plan sponsors to exclude certain specialty medications from a beneficiary's health plan coverage.<sup>5-7</sup> The AFP vendors then seek alternative sources to obtain the patient's medication. Typically, the alternative sources are PAPs or foundations, or they may include sources outside of the United States.<sup>5,7</sup> The use of AFPs thus far has been limited, with 14% of employers and 7% of health plans reporting using AFPs in 2023. However, there is potential for these programs to grow, with an additional 14% of employers and 33% of health plans reporting exploring their use.<sup>8</sup>

Some concerns have been raised around these programs. There are ethical considerations of diverting limited resources from PAPs and charitable foundations away from patients without insurance, who rely on these programs as a critical safety net and instead give them to insured patients. Furthermore, the AFP process of coverage denial and subsequently applying for aid can take time leading to potential treatment delays and disruption.<sup>4-6</sup> Lastly, there is additional administrative complexity for patients to obtain their medication via the AFP process, as well as privacy concerns, which may result in a negative experience for plan beneficiaries.<sup>4,9</sup> Although these concerns are potentially alarming, there has been no systematic research to support these hypotheses to date. To further understand the impact of AFPs, we conducted a patient survey to gather patients' experiences with the AFP process and their medication access through AFPs.

# **Methods**

A cross-sectional survey was conducted between October and December 2023. This study used convenience sampling to concurrently recruit participants from the Rare Patient Voice (RPV) patient panels and the Hope Charities (HOPE) patient advocacy group. In previous studies, RPV patient panels have been used across multiple disease areas,<sup>10-12</sup> and in the present study they were included to survey patients across conditions that may be treated with specialty medications. The HOPE patient advocacy group was used primarily to survey patients with hemophilia because there have been anecdotes of these patients being impacted by AFPs.<sup>13,14</sup> RPV used a panel method to prevent duplicate responses, and duplicate responses from HOPE were mitigated via internet protocol (IP) tracking from Qualtrics, which prevented respondents from the same IP address completing the survey twice. Additionally, patient demographic responses were evaluated for potential duplicative participation from each data source. Respondents received financial compensation for their participation.

To identify patients who had experience with AFPs, we developed a 4-item screening tool (Supplementary Table 1 and Supplementary Exhibit 1, available in online article). Patients were required to have employer-sponsored or union-sponsored health insurance and a chronic condition requiring a specialty medication. The specialty medication had to be excluded from their insurance coverage (but not if it was part of step therapy), and patients had to acquire it by contacting an AFP vendor to help them enroll in a PAP. Only adults (aged >18 years) were eligible to complete the survey, including caregivers who completed the survey on behalf of patients aged younger than 18 years.

Eligible patients were invited to complete a survey comprising 26 single-choice and multiple-choice, closed-ended questions, any of which patients could opt out of answering (Supplementary Exhibit 2). The survey was developed by the Partnership for Health Analytic Research in collaboration with HOPE and Genentech. The questions aimed to explore patient challenges with AFPs, including potential impacts on access to therapies. The questions were developed following conversations with individuals familiar with AFPs, in order to better understand the interactions between patients and AFPs and to obtain examples of challenges patients commonly face with AFPs, including those associated with treatment access and added costs. The survey was divided into the following 5 sections: "Change in specialty medication coverage," "Patient assistance program application process," "Medication access," "Other challenges," and "Demographics." Although the survey was not formally pilot tested, the content was reviewed by HOPE for comprehension from a patient perspective and was updated based on the input received. The study protocol, screening tool, and survey were reviewed and approved by the Western Institutional Review Board.

The survey was administered via Qualtrics, and data were analyzed descriptively (proportions, means, and medians) using SAS version 9.4 (SAS Institute Inc); no statistical analyses were conducted for the primary analysis. Where a participant skipped optional questions, this was considered missing data and excluded. Statistical analyses were carried out for exploratory subgroup analyses, which were conducted by disease area (for those subgroups with  $\geq$ 30 respondents) and annual income (<\$50,000 vs >\$50,000). All tests were 2-sided and P less than 0.05 was considered significant.

# Results

### **PATIENT DEMOGRAPHICS**

Across RPV patient panels, 23,584 patients were invited to complete the screening tool, of whom 6,828 were screened (29% response rate). Meanwhile, the HOPE patient advocacy group advertised the survey via quick response code at a conference, sent it to their blast e-mail groups, and posted it on their website, resulting in 718 patients being screened (response rate could not be calculated). In total, 7,546 patients were screened and 231 of these patients had experience with AFPs and therefore were eligible to complete the survey. Of 231 patients, 227 provided consent and answered at least 1 question in the survey, resulting in a response rate of 98% (Supplementary Table 1). Most patients were aged at least 18 years (90% [190/211]), were male (70% [144/207]), were non-Hispanic White (71% [150/211]), and lived in a suburb near a large city (43% [89/209]) (Table 1). The most common health conditions reported were multiple sclerosis (22% [47/211]), cancer (15% [32/211]), and hemophilia/bleeding disorders (14% [30/211]). Around a quarter of patients (27% [57/211]) reported an annual income of less than \$50,000, 61% (129/211) more than \$50,000, and 12% (25/211) did not wish to report or did not know their income.

### PATIENT AWARENESS OF AFPs AS PART OF HEALTH INSURANCE COVERAGE

Most patients (61% [136/223]) reported that they first learned about AFPs when they attempted to obtain their specialty medication and discovered it was excluded from their health plan (Figure 1). Overall, 28% (62/223) of patients reported being told about AFPs by their employer, including 19% (42/223) of patients who reported their employer let them know an AFP would automatically be applied to all their employees' health plan, or were strongly encouraged or required to enroll in the AFP. Among patients encouraged or forced to enroll in AFPs, more than half (51% [20/39]) reported being uncomfortable with the pressure from their employer (Figure 2). Furthermore, more than half of patients (54% [115/213]) were uncomfortable discussing their medication needs or financial challenges accessing their medication with their employer.

Patient characteristics	<b>n</b> (%)ª				
Total	227 (100)				
Age, years	211				
<18	21 (10)				
18-34	61 (28.9)				
35-44	46 (21.8)				
45-54	50 (23.7)				
≥55	32 (15.2)				
Do not wish to report	1 (0.5)				
Unknown	16				
Gender	207				
Female	61 (29.5)				
Male	144 (69.6)				
Do not wish to report	2 (1.0)				
Unknown	20				
Race and ethnicity, n	211				
Asian/Pacific Islander/American Indian or Alaska Native <sup>ь</sup>	5 (2.4)				
Black <sup>b</sup>	18 (8.5)				
Hispanic, Latino, or Spanish origin of any race	22 (10.4)				
Race and ethnicity not listed or do not wish to report	12 (5.7)				
Two or more races <sup>b</sup>	4 (1.9)				
White <sup>b</sup>	150 (71.1				
Unknown	11				
Yearly income, n	211				
<\$25,000	19 (9.0)				
\$25,000-\$50,000	38 (18.0)				
\$50,000-\$75,000	44 (20.9)				
\$75,000-\$100,000	46 (21.8)				
>\$100,000	39 (18.5)				
Do not wish to report or do not know	25 (11.8)				
Unknown	16				
Type of community, n	209				
Large city	46 (22.0)				
Suburb near a large city	89 (42.6)				
Small city or town	49 (23.4)				
Rural area	24 (11.5)				
Do not wish to report	1 (0.5)				
Unknown	18				
Health condition, n <sup>c</sup>					
Arthritis	21 (10.0)				
Cancer	32 (15.2)				

continued on next page

Survey Sample Demographics (continued)								
Crohn's disease, ulcerative colitis, disease	or other GI 18 (8.5)							
Hemophilia or other bleeding disc	order 30 (14.2)							
Multiple sclerosis	47 (22.3)							
Skin condition (such as psoriasis o	r eczema) 10 (4.7)							
Other rare disease not mentioned	above 38 (18.0)							
Other nonrare disease not mentio	ned above 9 (4.3)							
Do not wish to report	6 (2.8)							
Unknown	16							

"Unknown" are respondents who did not answer the question.

<sup>a</sup>Proportions may not total 100 because of rounding.

<sup>b</sup>Not Hispanic, Latino, or Spanish origin.

<sup>c</sup>Condition that a patient's excluded specialty medication was intended to treat. GI=gastrointestinal.

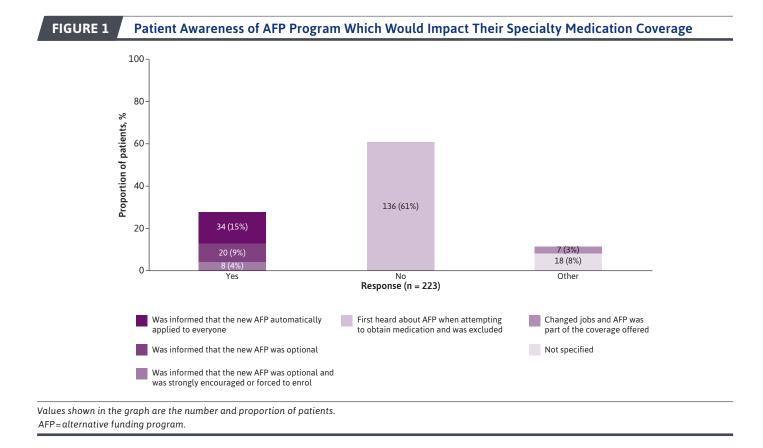
# PATIENT EXPERIENCES WITH THE AFP VENDOR AND PAP APPLICATION PROCESS

Almost 9 out of 10 patients (88% [174/198]) reported being stressed by their medication coverage being denied and the uncertainty of obtaining their medication. Additionally, 71%

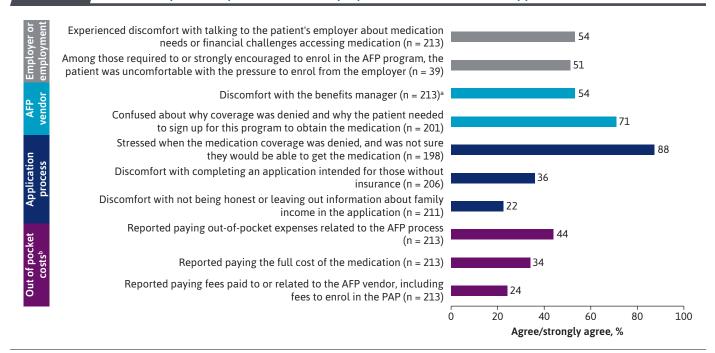
(143/201) of patients reported confusion over why their coverage was denied and why they needed to sign up with the AFP vendor to obtain their medication. More than half of patients (54% [115/213]) reported being uncomfortable with the benefits manager (person who is employed by the AFP vendor and in direct contact with patients) from the AFP vendor for 1 or more reasons, including medication needs (26% [30/115]), financial challenges (27% [31/115]), providing sensitive information (31% [36/115]), and confusion as to who they were (40% [46/115]). Lastly, 44% (94/213) of patients reported paying an out-of-pocket expense related to the AFP process, including 34% (72/213) who paid the full cost of the medication and 24% (51/213) who paid fees related to the AFP vendor (including fees to enroll in the PAP).

#### PATIENTS' ACCESS TO SPECIALTY MEDICATION

On average, patients reported a mean±SD waiting time to receive their medication of approximately 68.2±72.7 days (median 45.0 days). Patients indicated that the delay in receiving medication had negative impacts, with 24% (51/215) reporting that their condition worsened and 64% (138/215) reporting that the wait led to stress and/or anxiety (Table 2). The mean±SD wait time was approximately 2



### FIGURE 2 Patient-Reported Experiences with Employer, AFP Vendor, and PAP Application Process



<sup>a</sup>Talking to them about medication needs or financial challenges, providing them with sensitive information, or were confused about who they were. <sup>b</sup>These statements were multiple choice, and all that were true could be selected. AFP=alternative funding program; PAP=patient assistance programs.

## TABLE 2 Impact of

# Impact of Waiting for Specialty Medication Among Patients Who Answered Whether the Wait for Their Medication Had a Negative Impact on Their Health

		Impact of wait for specialty medication <sup>a</sup>					
Measure	Overall	Worsened condition	Stressed/anxious	No impact			
Impact of wait for specialty medication, n (%)	215 (100)	51 (24)	138 (64)	49 (23)			
Time to receiving or waiting for medication, n	200	48	129	44			
Mean ± SD, days	68.2±72.7	95.3±96.2	71.3±76.5	43.0±41.7			
Considered leaving their job because of health insurance, <sup>b</sup> n	198	48	128	43			
n (%)	59 (29)	18 (38)	44 (34)	3 (7)			
Left their job because of health insurance <sup>b</sup>	202	46	128	48			
n (%)	26 (13)	9 (20)	16 (13)	2 (4)			

<sup>a</sup>Proportions are based on respondents who answered whether the wait for their medication had a negative impact on their health (respondents possible responses were: "Yes, not having the medication has made my/the patient's condition worse," "Yes, I and/or the patient have been stressed or anxious," and "No") and the subsequent question of interest in the table rows.

<sup>b</sup>Number of respondents who "strongly agreed" or 'agreed' with the relevant statement.

times longer for patients with worsened condition or stress and/or anxiety resulting from wait time than patients who reported no impact (95.3±96.2 and 71.3±76.5 days vs 43.0±41.7 days, respectively). The patients who experienced a negative impact from the delay in receiving medication also reported considering a job change or leaving their job at 3-fold to 5-fold higher rates than those who reported no impact from the wait time (considered leaving job or left their job owing to health insurance, respectively: worsened condition, 38% [18/48] and 20% [9/46]; stress and/or anxiety, 34% [44/128] and 13% [16/128]; no impact, 7% [3/43] and 4% [2/48]).

# EXPLORATORY ANALYSES BY DISEASE AREA AND INCOME

Compared with all other respondents, a significantly lower proportion of patients with hemophilia reported receiving their originally prescribed medication (81% [52/64] vs 63% [19/30], respectively; P=0.022) and having their initial PAP application approved (67% [35/64] vs 26% [5/30]; P < 0.001) (Table 3). Additionally, compared with all other patients, a significantly greater proportion of patients with hemophilia reported being stressed and/or anxious as a result of waiting for their medication (61% [35/57] vs 90% [27/30], respectively; P=0.001). Compared with all other patients, a greater proportion of patients with hemophilia reported not receiving any medication (5% [3/64] vs 23% [7/30]; P=0.955) and reported longer mean±SD waiting times to receive their medication (66.0  $\pm$  72.2 vs 83.7  $\pm$  78.7 days, respectively; P=0.222); however, these results were not significant.

Exploratory analyses showed differences between patient groups according to the level of income, although no results reached statistical significance. Compared with patients reporting an income greater than \$50,000, a slightly greater proportion of patients with incomes less than \$50,000 reported not receiving their medication at all (5% [7/129] vs 12% [7/57]; P=0.657) (Table 3). Furthermore, patients with lower incomes waited longer mean±SD times for their medication than patients with higher incomes ( $81.0\pm94.8$  vs  $67.7\pm67.9$  days; P=0.367) and reported considering leaving or having left their jobs because of their insurance coverage at a higher rate (44% [14/32] vs 33% [21/63]; P=0.147).

# Discussion

In this cross-sectional descriptive survey, we found that the AFP process added confusion and complexity for some respondents seeking to obtain their medication. Some patients reported experiencing prolonged wait times to obtain their medicine, causing them additional stress and worsening their health conditions. These findings have implications for both employers and their employees.

Our findings detailing the delays in patients accessing their specialty medication aligns with previous commentaries that have hypothesized that AFPs might result in treatment delays and/or disruption.<sup>4,5</sup> We found that the average time to receipt of therapy because of medication delay was 68.2 days, approximately 2 months (median 45.0 days or 1.5 months), which is considerably longer than the wait time reported in the literature to obtain cancer medications without AFP involvement (median 6-15 days)<sup>15,16</sup> or specialty medications within specialty pharmacies (means of 2-7 days).<sup>17-19</sup> Given the seriousness of the conditions treated by specialty medications, delays in accessing medication may have significant clinical consequences. In metastatic nonsmall cell lung cancer, previous research has shown that a delay in treatment initiation of as little as 3 weeks may be associated with a greater than 2-fold higher risk of death.20 In early stage cancers, delays in adjuvant treatment may be associated with up to a 13% higher risk of death.<sup>21</sup> Overall, 24% of respondents within our survey self-reported that their condition worsened as a result of waiting for their medication. Additionally, it should be noted that across all conditions reported in this study, most patients reported greater stress and/or anxiety, and many patients with chronic illnesses already have preexisting or develop mental health conditions as a result of their disease.<sup>22</sup> Therefore, close attention should be paid to supporting the mental health of patients using AFPs.

In exploratory subgroup analyses, we found trends suggesting that patients' experiences may vary by disease state. In particular, based on the survey responses, patients with hemophilia experienced more challenges accessing their medicine and heightened stress and/or anxiety. Delays or interruption in hemophilia treatment are impactful because regular treatment prophylaxis is associated with lower risk of bleeding compared with on-demand treatment.<sup>23</sup> Furthermore, compared with the general population, patients with hemophilia have been shown to have an increased risk of mental health conditions such as depression and anxiety.<sup>24</sup> Additional stress and/or anxiety among patients with hemophilia may worsen quality of life and be associated with an increased risk of bleeding and hospital visits.<sup>25</sup>

Findings in the study have several implications in addition to the need for employers and plan sponsors to support their beneficiaries' or employees' mental health. First, most patients reported a lack of awareness regarding the changes in their health plan that require them to use an AFP vendor to obtain their medication. This suggests that there is a continued need for employers to be more mindful about sharing

TABLE 3

#### Exploratory Analyses by Disease Area and Income Levels

	Disease area							Income			
Accessing medication <sup>a</sup>	Overall	Cancer	Hemophilia, or other bleeding/ blood disorder	Multiple sclerosis	Other rare disease	Other/NR	P value⁵	<\$50,000	>\$50,000	NR	P value <sup>c</sup>
Receipt of medication, n (%)	211 (100)	32 (15)	30 (14)	47 (22)	38 (18)	64 (30)	0.024	57 (27)	129 (61)	25 (12)	0.255
Received originally prescribed medication	167 (79)	25 (78)	19 (63)	36 (77)	35 (92)	52 (81)		43 (75)	103 (80)	21 (84)	
Switched medications	29 (14)	5 (16)	4 (13)	8 (17)	3 (8)	9 (14)		7 (12)	19 (15)	3 (12)	
Did not receive any medication by the time of the survey	15 (7)	2 (6)	7 (23)	3 (6)	0 (0)	3 (5)		7 (12)	7 (5)	1 (4)	
Method by which the medi- cation was received, n <sup>d</sup>	167	25	19	36	35	52	0.0225	43	103	21	0.05
Initial application to PAP approved	104 (62)	15 (60)	5 (26)	27 (75)	22 (63)	35 (67)		25 (58)	69 (67)	10 (48)	
≥2 applications to PAP or different PAP approved	26 (16)	6 (24)	7 (37)	3 (8)	3 (9)	7 (13)		13 (30)	10 (10)	3 (14)	
Other method <sup>e</sup>	37 (22)	4 (16)	7 (37)	6 (17)	10 (29)	10 (19)		5 (12)	24 (23)	8 (38)	
Average wait time for medication, days, n	196	29	29	43	34	61		51	122	23	
Mean±SD	68.6±73.3	59.7±67.4	83.7±78.7	57.5±48.6	70.1±89.4	72.6±78.4	0.590	81.0±94.8	67.7±67.9	46.0±30.4	0.367
Median (interquartile range)	45 (28-84)	28 (28-112)	56 (28-112)	43 (25-84)	48 (28-84)	45 (28-84)		56 (28-84)	45 (28-84)	35 (21-56)	
Range	(4-504)	(4-305)	(5-336)	(7-197)	(7-504)	(10-364)		(7-504)	(4-364)	(7-112)	
Patients reporting stress/ anxiety because of wait for medication, n	211	32	30	47	38	64		57	129	25	
n (%)	136 (64)	23 (72)	27 (90)	25 (53)	25 (66)	36 (56)	0.008	35 (61)	83 (64)	18 (72)	0.701
Patients considering leaving or have left their job because of the insurance coverage'	207	32	29	45	38	63		56	126	25	
n (%)	67 (32)	14 (43.8)	16 (55.2)	7 (15.6)	9 (23.7)	21 (33.3)	0.003	24 (43)	40 (32)	3 (12)	0.147

Data are presented for only patients who responded to the disease area or income question and the question of interest.

<sup>a</sup>Proportions may not total 100 because of rounding.

<sup>b</sup>P value across the 5 groups.

<sup>c</sup>P value for less than \$50,000 vs more than \$50,000.

<sup>d</sup>Originally prescribed medication.

ePatient paid directly, employer made an exception, or patient changed jobs.

<sup>f</sup>Agreed or strongly agreed with this statement.

NR = not reported; PAP = patient assistance program.

these updates with their employees. Furthermore, patients reported being uncomfortable with several topics related to the AFP process, including discussing personal information (such as health or finances) with their employer, feeling pressure to enroll in the AFP, and the AFP vendor themselves. Taken together, these findings suggest that AFPs may negatively impact the employee–employer relationship. To further support this statement, a proportion of patients reported that they considered leaving or actually left their job, especially among those whose condition worsened or who reported stress and/or anxiety because of the wait for their medication. This may have particularly important implications in job markets with high competition for talent or where employee retention is critical. Lastly, stratified by income, although the results were not statistically significant, there were trends suggesting differences between higher and lower wage employees regarding the experiences with obtaining their medications via AFP vendors. Although these findings are exploratory and should be interpreted with caution, it may be important for employers to consider whether the addition of AFPs into their health benefits could lead to disparities in access to specialty medication for their employees. Moreover, the findings in this study are based on a small sample size of respondents, thereby limiting the generalizability of the results. Additional research is warranted to further explore any potential discriminatory effect AFPs may have for patients, because research into AFPs is lacking. The findings from our study may be the basis for future research into these programs and their impacts.

#### LIMITATIONS

The survey methodology used in this study has a number of limitations to consider, including being selfreported (therefore prone to bias), using a convenience sample from 2 different sources, and having a limited sample size. The inclusion of a control group to enable comparisons and understand potential biases would have been ideal; however, this was not possible in this study in part because of the lack of prior information available on potential sample size, because there were no previous studies at the time with a similar design. Direct comparisons in the primary analysis were not possible in this study, but for some metrics (such as time to obtaining treatment), we were able to reference the literature to contextualize our results. Nonetheless, future research examining the impact of AFPs should consider the inclusion of a control

group to better understand differences in delays in medication access and its effects. In addition, as mentioned, our study was limited in sample size because of the relatively low prevalence of AFPs, despite attempting to maximize the sample size by screening more than 7,500 patients from 2 data sources. Additionally, the branching and optional questions led to smaller response numbers for certain questions. Because subgroup analyses were limited in sample size, with only 30 patients with hemophilia participating, these should be considered exploratory. Despite the sample size limitations, this study offers the first insights into patients' experiences with AFPs and can therefore be considered foundational for other research to leverage and expand upon. Lastly, given that a convenience sample of self-reporting patients was used, the generalizability of the results may be limited and only be applicable to those who answered the survey. Because this is the first study surveying patients who had experience with AFPs, the direction of any potential bias is unknown. Further research with additional populations is needed to be able to compare these findings.

# Conclusions

Among patients participating in this survey study, most who obtain their specialty medicines via AFPs reported being uncomfortable with the process and experienced treatment delays, which may lead to disease progression, additional stress and/ or anxiety, and consideration of a job change. Employers should be aware of the potential downstream impacts on employee retention and the employee–employer relationship when considering implementing an AFP into their health plan.

#### DISCLOSURES

This study was funded by Genentech, Inc. Genentech, Inc. were involved in conducting the study. Dr Wong is an employee of Genentech, Inc. and has Roche stock/ stock options. Dr Yermilov, Ms Dalglish, and Ms Gibbs are employees of Partnership for Health Analytic Research, which was paid by Genentech, Inc., to conduct the research described in this manuscript.

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