

# Access to Specialty Medicines with Alternative Funding Programs: A Descriptive Survey of Patient Experience

Hannah Dalglish, MPH<sup>1</sup>, Sarah N Gibbs, MPH<sup>1</sup>, Irina Yermilov, MD, MPH, MS<sup>1</sup>, Lori Bienvenu, MS, LPC<sup>2</sup>, Jonathan James<sup>2</sup>, William B. Wong, PharmD, MS<sup>3</sup>

<sup>1</sup>Partnership for Health Analytic Research; <sup>2</sup>HOPE Charities; <sup>3</sup>Genentech, Inc.



## BACKGROUND & OBJECTIVE

- Alternative funding programs (AFPs) attempt to lower plan sponsor costs by excluding expensive 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 AFPs 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>
- Patients' experiences with, and access to, medicines through these AFPs have not been previously described.

**The objective of this study was to describe patients' experiences with and access to specialty medications through AFPs. 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

## 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 Charities (HOPE) patient advocacy group.
- Only patients eligible based on a 4-item screener were invited to complete the survey (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).
- The survey was administered via Qualtrics, and all responses were analyzed descriptively (proportions, means) and reported only for patients who responded to the question(s).
- A total of 7,546 patients completed the screener and 227 patients were included in the final sample (**Table 1**).

## RESULTS

### Overall Sample

**Table 1. Survey Sample Demographics**

Patient Characteristics	N=227	%
<b>Age</b>		
≤34	82	38.9%
35-44	46	21.8%
45-54	50	23.7%
55+	32	15.2%
Do not wish to report	1	0.5%
<b>Gender</b>		
Female	61	29.5%
Male	144	68.6%
Do not wish to report	2	1.0%
<b>Race and Ethnicity</b>		
Asian/Pacific Islander/American Indian or Alaska Native, not Hispanic, Latino, or Spanish origin	5	2.3%
Black, not Hispanic, Latino, or Spanish origin	18	8.5%
Hispanic, Latino or Spanish origin of any race	22	10.4%
Race/ethnicity not listed or do not wish to report	12	5.7%
Two or more races and not Hispanic, Latino, or Spanish origin	4	1.9%
White, not Hispanic, Latino, or Spanish origin	150	71.1%
<b>Yearly Income</b>		
< \$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 don't know	25	11.8%
<b>Health Condition (i.e., condition patient's excluded specialty medication was intended to treat)</b>		
Arthritis	21	10.0%
Cancer	32	15.2%
Crohn's disease, ulcerative colitis, or other GI disease	18	8.5%
Hemophilia, or other bleeding disorder	30	14.2%
Multiple sclerosis	47	22.3%
Skin condition (such as psoriasis or eczema)	10	4.7%
Other rare disease not mentioned above	38	18.0%
Other non-rare disease not mentioned above	7	3.3%
Do not wish to report	6	2.8%

"Do not wish to report" represents participants who selected the response choice "do not wish to report."

### Patient Awareness of AFP Program as Part of Health Insurance Coverage

- Most patients (61%) did not learn about AFPs through their employer and instead first learned about them as part of their health plan benefit when trying to obtain their specialty medication.

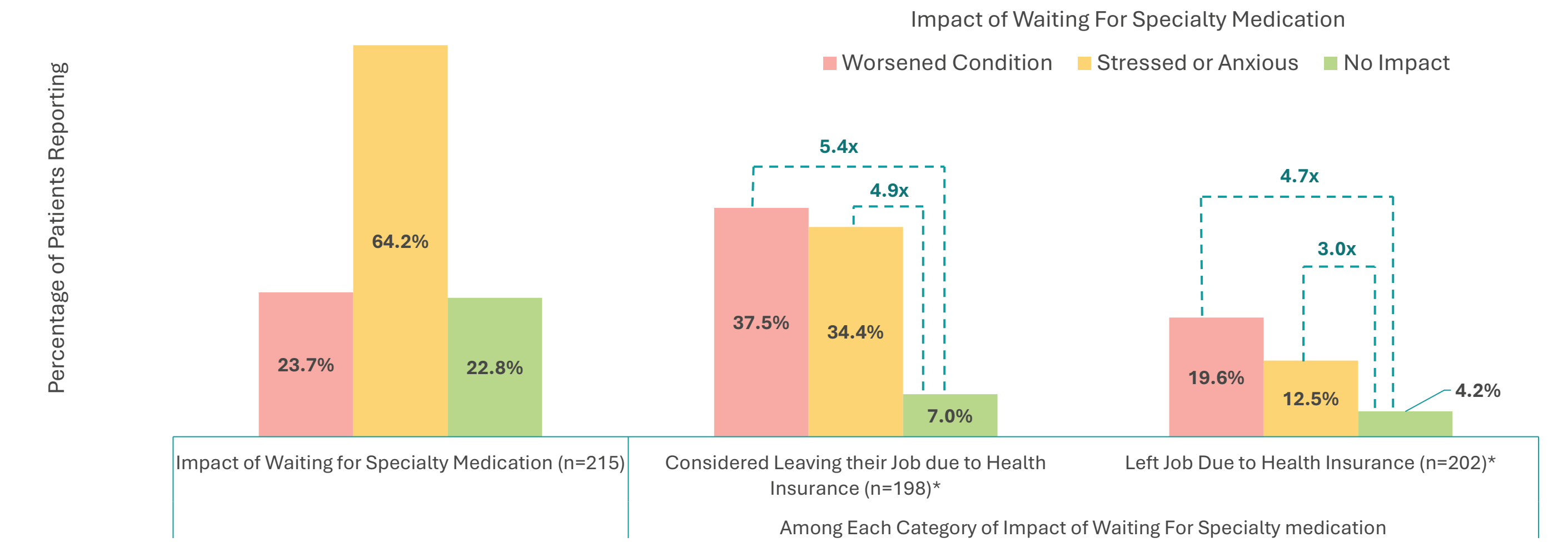
### Patient Experience with AFPs and Access to Specialty Medication

- Patients reported a mean wait time of approximately 2 months (68.2 days) to receive their medication.
- Patients reported that the wait time for their specialty medication negatively impacted their health (24% reported that waiting worsened their condition; 64% reported that waiting led to stress and/or anxiety) (**Figure 1a, 1b**).
- Patients who reported the wait time for their specialty medication negatively impacted their health considered leaving or had left their job at a rate 3-5 times higher than those who did not (**Figure 1a**).
- Eighty-eight percent of patients reported being stressed or anxious due to the medication coverage denial and the resulting uncertainty surrounding obtaining their medication.
- Over half of patients (54%) reported being uncomfortable with the AFP vendor representative, including feeling hesitant to provide them with sensitive information (**Figure 2**).

## LIMITATIONS

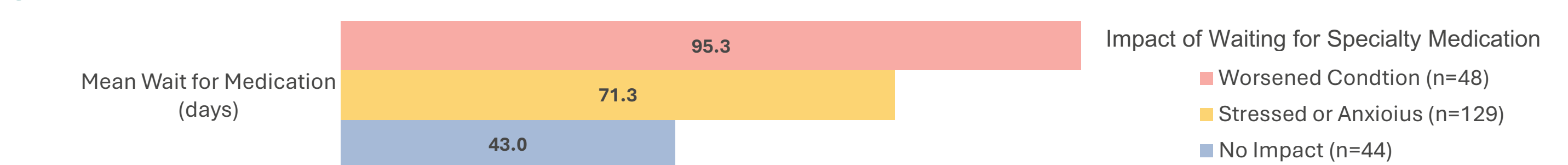
- The survey was self-report and relied on a convenience sample and was therefore prone to bias. This study also lacked a control group. While we screened over 7,500 patients from two data sources, our resulting study sample remained limited due to the relatively low prevalence of AFPs. Lastly, survey branching and optional questions led to smaller numbers for certain questions.

**Figure 1a. Impact of Waiting for Specialty Medication and Relationship to Employment Changes Due to Health Insurance**



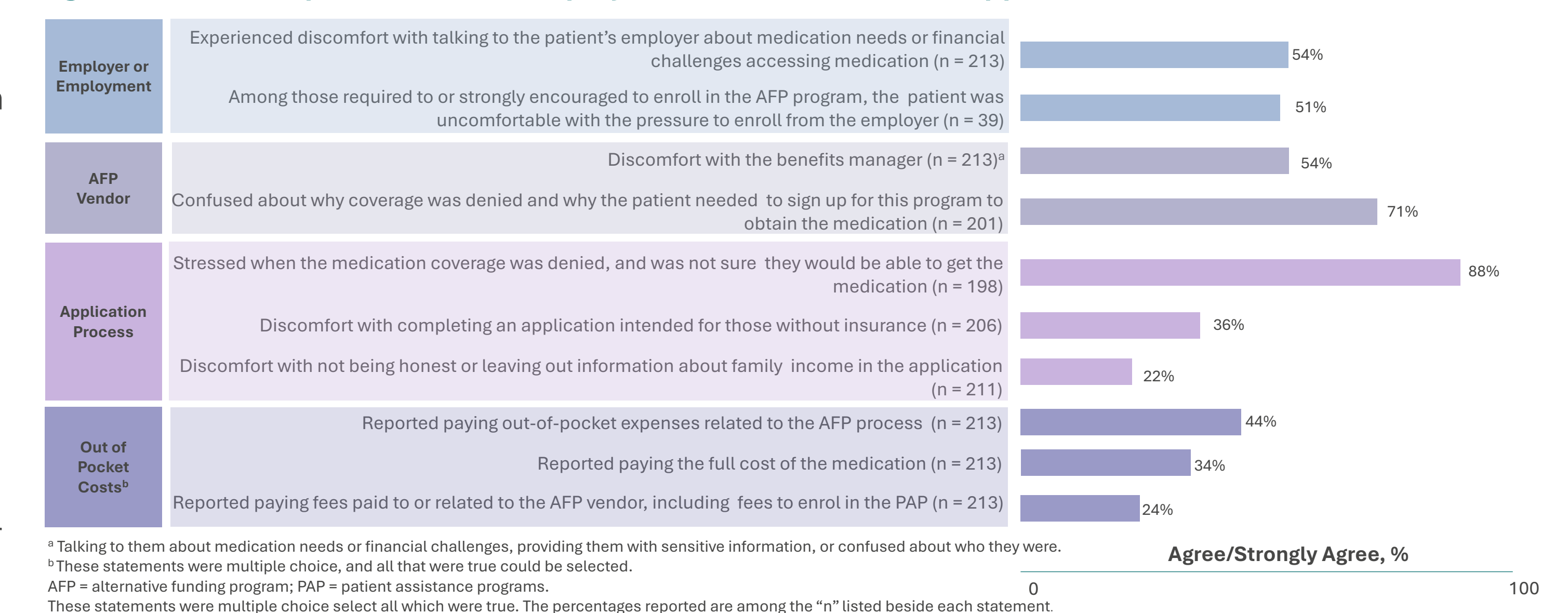
\*Proportions indicate reported effect among respondents who indicated they had a wait time for their specialty medication (left). Data are reported only among respondents who answered all questions of interest.

**Figure 1b. Impact of Mean Wait Time for Specialty Medication**



Graph represents a cross-section of the data in Fig. 1A (above). Wait times are either to receive medication if obtained or an ongoing wait time for medication if not obtained at time of survey. Data are reported only among respondents who answered all questions of interest.

**Figure 2. Patient 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 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.

These statements were multiple choice select all which were true. The percentages reported are among the "n" listed beside each statement.

## KEY TAKEAWAYS

- Most patients obtaining their specialty medicines via AFPs reported being uncomfortable with the process and had delays in obtaining their medication, which may be linked to heightened stress and/or anxiety, worsening disease progression, and consideration of a job change.
- Employers should carefully consider potential delays in medication access and impacts on employee retention, as well as overall employee-employer relationships when considering implementing an AFP into their health plans.

<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>.