

# State of Patient Access

2024 REPORT



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# **Executive Summary**



### **Executive summary**

Healthcare in the United States has become unaffordable and inaccessible for many patients, even those with health insurance and other resources. Though disparities run deep and wide—rooted in racism and bias, structural inequities, social and economic disadvantages, and systemic inefficiencies—challenges accessing and affording needed healthcare have become all too common for everyone. For patients with chronic health conditions, access to care is especially important to maintaining health and well-being. Too often, costs, coverage issues, and interpersonal barriers prevent patients from getting the high-quality care they need and deserve.



#### EXECUTIVE SUMMARY

### About the State of Patient Access initiative

To further explore healthcare access challenges and their impact on different communities, the PAN Foundation launched the *State of Patient Access* initiative in 2024. This cornerstone research illuminates barriers to care through two national surveys conducted by The Harris Poll in August–September of 2023, one among 2,502 patients with chronic conditions (referred to as "patients" throughout) and one among healthcare professionals (HCPs), including 251 primary care providers (PCPs), 150 nurse practitioners (NPs) or physician assistants (PAs), and 100 registered nurses (RNs). The surveys were organized around five key areas, including:

- 1. Overall Access to Care
- 2. Relationship with Healthcare Professionals
- 3. Affordability of Prescription Medications
- 4. Access to Treatment through Healthcare Plans
- 5. Financial Toxicity

### **Key findings**

To assess the state of patient access in the United States, we synthesized the patient survey results into a *2024 State of Patient Access Scorecard*, organized across five key areas. We calculated an overall composite index score across categories, with individual scores for each subcategory as well. The scores were calculated both at the total patient level, and for a variety of subgroups within the broader patient population to highlight any disparities in access to care.



#### EXECUTIVE SUMMARY High-level findings for each component of the scorecard include:

### 1. Overall access to care is challenging for everyone, but even worse for historically marginalized communities.

Earning just a "C+" on the scorecard, our *Overall Access to Care* measure reflects that nearly one in five patients gave their healthcare access a "C" (18%) and rated the quality of care they had received in the past year as poor or fair (17%). Nearly half (48%) of patients faced logistical barriers to care, including trouble getting appointments, getting to appointments, and getting coverage or financial assistance for needed care. Slightly more than half (52%) said they wish they had help navigating those barriers. People of color, younger patients (Gen Z or Millennials), and patients within the LGBTQIA+ community, are all more likely to report barriers to care. Two in five (38%) patients reported feeling that some aspect of their identity—such as their race/ethnicity, age, gender identity, or income—negatively impacted their ability to get the best possible care.



### 2. Despite high trust in healthcare professionals, patient-provider relationships can be challenging.

The *Relationship with Healthcare Professionals* measure earns a "B," in part thanks to high trust in healthcare professionals (HCPs). The vast majority of patients surveyed trust their HCPs, with 96% saying they trust their primary care physician (PCP), 95% their specialist, and 94% both their nurses and nurse practitioners (NP)s or physician assistants (PAs). Nonetheless, there is room for improvement: 28% of patients experienced challenges in their HCP interactions, such as 11% of patients who said they feel their HCP does not take their concerns seriously.



Healthcare Professionals

#### EXECUTIVE SUMMARY High-level findings for each component of the scorecard include:

#### 3. Many patients struggle to afford or obtain medications due to cost. Access to prescription medications is even harder for Hispanic, Native American or Pacific Islander, and LGBTQIA+ patients.

The *Affordability of Prescription Medications* measure earned a "B-" in our scorecard, one of the better grades. Nonetheless, 20% of patients said that their prescriptions were not affordable, and 36% had taken some financial steps, such as reducing other spending (15%) or taking on credit card debt (11%), to pay for medications. Nearly one in five (17%) could not get their medicines in the past year because of cost.

Of those, 94% took a related action, such as not filling the prescription (55%) or rationing their doses (26%). Most (79%) patients who did not get their medications because of cost experienced negative impacts, including negative impact to their physical or mental health (34%) or delayed treatment (14%). One-third (33%) said they are worried about affording prescriptions in the future.

### 4. Access to treatment through insurance—both public and private—is one of the greatest challenges patients face today.

Across all patients, *Access to Treatment through Healthcare Plans* received a "D-" but fell to a failing grade of an "F" among Hispanic, Native American or Pacific Islanders, LGBTQIA+ patients, as well as younger patients (Gen Z or Millennials) and those with lower incomes (less than \$50K). Affordability, administrative or policy hassles, and fear that drug coverage will get worse contribute to the ratings. Half (49%) of patients had challenges related to their health plan, such as prior authorization requirements or high out-of-pocket costs. Deductibles presented particular affordability challenges, with 36% of patients worried about paying their deductible next year. Most (58%) are also worried their health plan will make it harder to access prescriptions in the future, a sentiment felt more acutely among those with private insurance<sup>1</sup> (18% strongly agree) compared to those with public insurance<sup>2</sup> (12%). Privately insured patients (22%) were also more likely than patients on public insurance (17%) to report difficulty paying for prescriptions in the past 12 months.



Affordability of Prescription Medications



Access to Treatment through Healthcare Plans

<sup>1</sup>Private Insurance: Coverage provided by private companies and purchased by individuals or employers to meet healthcare needs.

<sup>2</sup> Public Insurance: Coverage provided by government-funded programs, such as Medicare and Medicaid, designed to offer healthcare benefits to eligible individuals.

#### EXECUTIVE SUMMARY High-level findings for each component of the scorecard include:

### 5. Health insurance does not sufficiently protect people from financial toxicity—regardless of insurance type.

Our study defines financial toxicity as "the emotional, mental, and physically debilitating—and often life-threatening—financial side effects and burdens associated with treatment for your chronic condition(s)." The *Financial Toxicity* measure of our scorecard earned a "C-," reflecting the extent of financial hardship, anxiety, and negative impacts caused by healthcare costs. Overall, nearly one-quarter (22%) of patients said that financial toxicity impacted them a great deal or a lot. Patients of color, members of the LGBTQIA+ community, and younger patients reported higher rates of financial toxicity than others. Similar rates of patients on private (21%) and public (23%) insurance said they experienced high levels of financial toxicity.



Our findings show that even patients with health insurance coverage face financial burdens, financial anxiety, and the negative effects of the cost of care. Sometimes, insurance coverage that is supposed to protect people financially can create financial distress. These obstacles often interfere with access to medications and other healthcare services, a reality that cuts across demographic groups. The *State of Patient Access* study supports the need to increase equitable access to affordable healthcare and improve patient outcomes through awareness, education, and impactful policy solutions. HCPs, health plans, patient groups, policymakers, and other stakeholder groups can all play a role in reducing barriers and disparities.



# Introduction and overview



### Introduction and overview

Healthcare in the United States has long been considered "the best in the world"—but only for those who could access it. Social and economic disadvantages, often rooted in racism and discrimination, have led to different healthcare realities for different segments of the population. Disparities based on race, ethnicity, language, sex and gender identity, sexual orientation, geography, and other sociodemographic factors have always been embedded in the healthcare system. Increasingly, these factors are explicitly recognized as critical contributors to unequal access to healthcare, positive health outcomes, and even life expectancy.

Access to high-quality, affordable healthcare services is key to individuals' health and well-being. Too often, though, costs, bureaucracy, communication and education gaps, and bias prevent people from getting the best possible care. To quantify barriers to needed healthcare services and treatments, the PAN Foundation launched the *State of Patient Access* initiative in 2024. This groundbreaking initiative includes a comprehensive survey conducted by The Harris Poll in August–September 2023 among 2,502 adults with chronic health conditions and a companion survey among healthcare professionals (HCPs), including 251 primary care providers (PCPs), 150 nurse practitioners (NPs) or physician assistants (PAs), and 100 registered nurses (RNs).

We asked patients to share their experiences accessing care, including specific challenges they have faced in doing so. The study is based on the following grouping of questions:

- 1. **Overall Access to Care**
- 2. Relationship with Healthcare Professionals
- 3. Affordability of Prescription Medications
- 4. Access to Treatment through Healthcare Plans
- 5. Financial Toxicity

The data provides in-depth illustrations of how patients view their own health and healthcare, and the barriers they experience across logistical, financial, and interpersonal lines.

The PAN Foundation will conduct this study annually to enable analysis of trends over time, identify disparities in care, and find opportunities to close gaps and advocate for change.

### INTRODUCTION AND OVERVIEW Background

The Patient Access Network (PAN) Foundation is a national patient advocacy organization whose mission is to help underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments they need and advocate for improved healthcare access, equity, and affordability. For the two decades since our founding, we have recognized that access to affordable and timely healthcare treatment and services is fundamental to improving individuals' health and well-being.

Unfortunately, social drivers of health and factors such as race, ethnicity, gender, sexual orientation, income, and geography often present barriers to treatment. These barriers impact individuals' ability to receive, access, and afford needed services, which in turn, can negatively impact their health.

Disparities in access and systemic inefficiencies contribute to a fragmented healthcare landscape, which further impedes access to high-quality care. As the nation strives to address these challenges, the pursuit of equitable and comprehensive healthcare for all stands as a paramount objective, necessitating a nuanced examination of policies, infrastructure, and the intersection of various social determinants of health.

The PAN Foundation is committed to understanding health disparities, developing programs that improve access to care, educating patients and healthcare professionals, and driving legislative and regulatory change to address needed policy solutions that improve access to care.

Through this inaugural *State of Patient Access* report, we aim to highlight the healthcare access challenges and inequities facing patients so we can collectively shape an action-oriented agenda to bring about needed change.



#### INTRODUCTION AND OVERVIEW

#### **Research objectives**

The PAN Foundation commissioned this study, conducted by The Harris Poll, in order to:

- Discover and confirm barriers that patients with serious and/or chronic diseases face when seeking essential medications, treatments, and other healthcare services
- Identify differences between the experiences of people in various groups and communities
- Create a baseline against which to measure changes annually to highlight areas of improvement over time

These findings are intended to support the efforts of the PAN Foundation and others to increase access to affordable healthcare and improve patient outcomes. Through comprehensive education and awareness of these challenges and barriers, we hope to inform policy solutions with a focus on affordability and access to services and treatments.

#### **Research methodology**

At the foundation of the State of Patient Access initiative are two national surveys among: 1) adults with chronic health conditions and 2) healthcare professionals (HCPs). Please see the appendix for the full methodology statements, including details on sampling precision and weighting.

#### Adults with chronic conditions

The patient research was fielded online by The Harris Poll on behalf of the PAN Foundation among 2,367 adults 18+ in the U.S. who have been diagnosed with a chronic health condition, plus 135 adults 18+ in the U.S. diagnosed with a chronic health condition who identify as LGBTQIA+. The survey was conducted in both English and Spanish.



Audience

2,502 U.S. adults 18+ diagnosed with a chronic health condition

Mode

20-minute

online survey



**Field Timing** Aug. 10-Sept. 6, 2023



Weighting Data are weighted to ensure results are projectable to broader population of U.S. adults with a chronic health condition

#### Healthcare professionals

The HCP research was fielded online by The Harris Poll on behalf of the PAN Foundation among 251 duly licensed primary care physicians (PCPs), 150 licensed nurse practitioners and physician associates/ physician assistants (NP/PAs), and 100 registered nurses (RNs) aged 18+ who have practiced in the U.S. for at least a year and who see at least 10 adult patients with a chronic health condition per month.



Audience

251 PCPs, 150 NP/PAs,

100 Nurses

Practicing for 1+ year(s)

& who see 10+ patients per month with a chronic health condition

Mode

20-minute

online survey

000 0000 0000

**Field Timing** Aug. 10-28, 2023



#### Weighting

Data are weighted to ensure results are projectable to the broader physician populations

#### INTRODUCTION AND OVERVIEW

#### **Demographics**

#### Patient sociodemographic characteristics

Patient survey respondents skewed slightly more women and older patients, representing a mix of racial and ethnic identities, geographic regions, and income and education levels. Highlighted patient demographics are below, with further details included in the appendix.



### Patient insurance status and type

Virtually all (96%) patients reported having health insurance. Of those, 68% had some form of private insurance and 36% had some form of public insurance. Nearly one in five (17%) had a change in health insurance coverage in the past year.

#### Source of health insurance



Note: Total exceeds 100% because participants were able to select multiple responses

#### Patient health conditions, severity, and health status

All patients had been diagnosed by an HCP with at least one chronic health condition. More than half (55%) had multiple chronic health conditions. While the average number was two, one in five (18%) participants had four or more, and 11% had five or more.

Most (87%) patients characterized their condition(s) as chronic, 7% reported having cancer, and 5% reported having a rare disease. Only 9% of patients said they have a severe health condition. Most rated their condition(s) as moderate (55%) or mild (36%). The average patient reported two chronic conditions. 1 in 5 patients had four or more diagnoses.



than one chronic condition, nearly one in five (18%) said that their mental health condition had the greatest negative impact on their quality of life. More detail on patient-reported conditions is included in the appendix.

Despite the presence of at least one chronic health condition, more than half (59%) of patients reported that their overall physical and mental health in the past 12 months was excellent or good. Still, that left two out of five (41%) describing their health as poor or fair.



Patients' overall health (physical and mental) in past 12 months

> **4 in 10 patients** describe their overall health as poor or fair.

33% said it was very/ somewhat difficult to receive an accurate diagnosis for their chronic health condition(s).

Certain patients had worse perceptions of their health. Sixty-one percent of LGBTQIA+ patients rated their mental or physical health as poor or fair, compared with 40% of non-LGBTQIA+ patients. More than half (57%) of LGBTQIA+ patients reported having at least one disability compared to non-LGBTQIA+ patients (37%).

Half (52%) of patients in lower-income households (less than \$50K) had poor or fair health status, compared with 35% of patients living in higher-earning households (\$50K or more). Though health insurance type did not seem to make a difference on most measures, 45% of patients with public insurance rated their health as poor or fair, compared with 36% of privately insured patients.

Compared to patients' self-assessments, HCPs were more likely to report that the patients they see, on average, are in poor or fair health (50% PCPs, 54% NP/PAs, 64% RNs), that they see a higher concentration of patients with multiple chronic conditions (60% PCPs, 67% NP/PAs, 73% RNs), and that their patients, on average, have more severe chronic health condition(s) (64% PCPs, 67% NP/PAs, 75% RNs).

#### Healthcare professional demographics

The HCP survey included three subsets of providers: primary care physicians (PCPs), nurse practitioners and physician assistants (NP/PAs), and other nurses (RNs). About half (51%) of PCPs and NP/PAs said they have a nurse care coordinator on staff, as did 72% of RNs. Most HCPs who see non-English speaking patients with a chronic condition said they have a staff member or members who can speak their patients' native language (63% PCPs, 64% NP/PAs, 80% RNs). Detailed demographics about each HCP segment are included in the appendix.



#### INTRODUCTION AND OVERVIEW

### 2024 State of Patient Access Scorecard

To crystallize the key findings from the patient survey and synthesize the state of patient access in the United States, we created a scorecard with five dimensions:

- Overall Access to Care
- Relationship with Healthcare Professionals
- Affordability of Prescription Medications
- Access to Treatment through Healthcare Plans
- Financial Toxicity

#### Index components

The *State of Healthcare Access* Index incorporates a variety of variables across five categories, each related to patients' ability to access needed healthcare and prescription medication.

 Any HCP interaction-related Prescription medication Could not get prescription Medication access challenge to needed care in challenges due to costs were not at all/not very medication in past 12 months past 12 months healthcare plan in past affordable in past 12 months due to high out of pocket costs 12 months Trust in PCPs/Nurses/NP/ Worried about prescription • Took any action as a result of PAs • Healthcare plan medication costs in next 12 not getting medication in the months past 12 months deductibles were not at • Agree that HCP sees them as all/not very affordable in a partner in treatment plan Very/somewhat difficult to pay
 Health implications as a result past 12 months for prescription medication of inability to get prescription Trust that HCP has their • Worried about healthcare costs in past 12 months medication in the past best interest in mind when plan deductibles in next 12 months. making healthcare decisions • Took any financial action to 12 months afford prescription medication · Desire help with finding resources to afford prescription • Agree that healthcare in past 12 months plan details are nearly medication impossible to understand Grade of ability · Agree they are worried to access needed healthcare in past 12 about health access getting more difficult in months Affordability of the coming years Access to Treatment • Quality of healthcare Prescription received in past 12 Relationship Medications months Healthcare plana withHCPS • Quality of healthcare coverage over the past 12 months Negative Impact to care in past 12 months Overall Access to Care Any logistical access The state of healthcare access A great deal/a lot challenges to needed of financial toxicity <sup>;inancial</sup> Toxicity among patients with care in past 12 months experienced due to cost of treatment Desire for help a chronic health condition with access related elements of healthcare

Each of the five categories were weighted equally and make up 20% of the overall index score

To arrive at an aggregate score for each domain, we used composite indices, which incorporate a variety of survey questions and response options, each assigned a weight. The weights assigned to each question or response option total 100 within each index category. Individual respondents were then assigned a score between zero and 100, based on their responses to the survey questions included in the indices. The average of all respondents' scores resulted in a composite index score, which summarizes a subset of attributes or dimensions into a single metric. Each metric synthesizes patients' views and experiences in a particular domain. The specific questions and weights used to create the index scores are included in the appendix.

# 2024 State of Patient Access findings



### 2024 State of Patient Access findings

#### 2024 State of Patient Access Scorecard



The 2024 State of Patient Access Scorecard provides a composite rating for each of five domains. The highest performing dimension is *Relationship with Healthcare Professionals*, which earned a "B" with an overall score of 84.2. The lowest is *Access to Treatment through Healthcare Plans*, earning a "D-" with a score of just 62.8.



Overall Access to Care



Relationship with Healthcare Professionals



Affordability of Prescription Medications



Access to Treatment through Healthcare Plans



Financial Toxicity

#### 2024 State of Patient Access Scorecard

Overall grades vary for different patient subgroups. For example, while the *Access to Treatment through Healthcare Plans* index category earned an overall grade of "D-," it was even worse for some patient populations. The index score was an "F" for Hispanic, Native American or Pacific Islander<sup>3</sup>, LGBTQIA+, Gen Z, Millennial, and patients with lower incomes. Similarly, whereas the overall *Financial Toxicity* score was a "C-," it was a "D-" for patients of color, Native Americans or Pacific Islanders, Gen Z, and patients with lower incomes.

	Total		I	Race/Ethnicit	у		Gender/Gen	der Identity	Gene	eration	Income
		Patients of Color	Black/ African American Patients	Hispanic Patients	Asian Patients	Native American/ Pacific Islander Patients	LGBTQIA+ Patients	Female Patients	Gen Z Patients (ages 18-26)	Millennial Patients (ages 27- 42)	Lower Income Patients (<\$50K)
Overall Grade	С	C-	С	C-	С	C-	D	С	D+	D+	C-
Overall Access to Care	C+	С	C+	С	С	C+	C-	C+	C-	С	С
Relationship with Healthcare Professionals	В	B-	B-	B-	В-	В	с	В	C+	C+	B-
Affordability of Prescription Medications	В-	C+	B-	С	В-	с	С	В-	С	С	B-
Access to Treatment through Healthcare Plans	D-	D-	D-	F	D-	F	F	D-	F	F	F
Financial Toxicity	C-	D-	D	F	C-	D-	F	D+	D-	F	D-
A+ 97-100       B+ 87-89       C+ 77-79       D+ 67-69       F 0-59         A 93-96       B 83-86       C 73-76       D 65-66         A- 90-92       B- 80-82       C- 70-72       D- 60-64											

<sup>3</sup> "Native American or Pacific Islander" refers to American Indian or Alaskan Native respondents (n=89) and Native Hawaiian or Other Pacific Islander respondents (n=11). Though we recognize that these are distinct groups, we combined them for the purposes of analysis and reporting due to the difficulty of reaching either of these groups independently and our desire to create a subgroup with a projectable base size of at least n=100 so these audiences can both have a voice in the research.

## 2024 STATE OF PATIENT ACCESS FINDINGS Overall Access to Care



The Overall Access to Care dimension of the 2024 State of Patient Access Scorecard includes questions related to how patients rated their access to healthcare and the quality of care and coverage they received. It also includes questions about patients' perceptions of the negative impacts that elements of their identity had on their care, logistical access challenges they experienced, and patients' desire for help accessing elements of care.

Based on patient responses to questions included in this domain, our findings suggest that access to care in the United States is fair at best. This sentiment was encapsulated in patients' assessment of their access to care. When asked to provide an overall letter grade for their ability to access the healthcare services they needed in the past year, only half (51%) said "A" and 18% graded their healthcare access as "C" or worse. Additionally, among patients with health insurance coverage, 13% said that their healthcare coverage had gotten worse compared to the previous year.

### Health disparities in action

There was relatively little variation in the scores for this domain across populations, though several groups had worse scores for *Overall Access to Care*. People of color overall—as well as Hispanic and Asian patients specifically—Millennials, and patients with lower incomes rated *Overall Access to Care* a "C," while LGBTQIA+ and Gen Z patients gave it a "C-."

	Total	Race/Ethnicity					Gender/Gender Identity		Generation		Income
		Patients of Color	Black/ African American Patients	Hispanic Patients	Asian Patients	Native American/ Pacific Islander Patients	LGBTQIA+ Patients	Female Patients	Gen Z Patients (ages 18-26)	Millennial Patients (ages 27- 42)	Lower Income Patients (<\$50K)
Overall Access to Care	C+	С	C+	С	С	C+	C-	C+	C-	С	С

Nearly 1 in 5 patients rated their ability to access healthcare services a grade of "C" or worse.

#### 2024 STATE OF PATIENT ACCESS FINDINGS **Overall access to care**



#### Quality of care and coverage

While 83% of patients rated the quality of care they received in the past 12 months as excellent or good, nearly one in five (17%) said it was poor or fair. Compared to white patients, patients of color were more likely to rate the quality of their care in more negative terms. Thirty percent of Asian patients and 23% of Hispanic patients said the overall guality of care they had received was poor or fair, compared with 15% of white patients.

Further demographic differences included LGBTQIA+ patients, 31% of whom rated the quality of their care as poor or fair, compared to 17% of non-LGBTQIA+ patients. Similarly, younger patients were significantly more likely than older ones to give the quality of their care low marks: 30% of Gen Z and 25% of Millennials rated their care as poor or fair compared with 19% of Gen X and 10% of Boomer/Silent Generation patients.

Nearly 1 in 5 patients say the overall quality of care they received was poor/fair.

#### Challenges getting accurate diagnoses

In one dimension of quality, many patients reported difficulties and delays getting a proper diagnosis. One-third of patients (33%) reported it was very or somewhat difficult to get an accurate diagnosis for their condition and 38% said it had taken one year or longer to get a diagnosis from the initial onset of their symptoms. The average time to get a correct diagnosis was three years-even longer (five years) for people with mental health conditions or chronic pain syndrome. HCPs reported shorter times, on average, than patients.



Time between initial onset of symptoms and diagnosis



#### **Overall access to care**

#### Logistical barriers

Patients reported facing a wide range of barriers to the care they need, from logistical challenges to costs and coverage issues. Nearly half (48%) of patients reported facing at least one logistical challenge. Approximately one in five (18%) patients said they had trouble getting an appointment and 10% had difficulty finding an HCP. Nearly as many said they could not find conveniently located care (9%) and struggled with transportation to appointments (8%). Others had difficulty getting time off work (8%), faced competing priorities such as childcare or other caregiving responsibilities (5%), and lacked access to internet/WIFI (3%) and devices (3%).

HCPs reported discussing many of these logistical barriers with their patients in the past 12 months. The most commonly discussed barriers were difficulties paying for needed prescription medications (77% PCPs, 76% NP/PAs, 80% RNs), and health plan restrictions (70%, 75%, 72%, respectively). Lack of transportation to appointments (62%, 64%, 77%, respectively), lack of caregiver support (56%, 57%, 68%, respectively), and difficulties getting an appointment (65%, 69%, 59%, respectively) were also frequently discussed.

### 48% reported facing at least one logistical challenge

Difficulty getting an appointment	18%
Financial difficulties in paying for needed care	13%
Health plan restrictions	13%
Financial difficulties in paying for needed prescription medication	10%
Difficulty finding a healthcare professional	10%
Lack of conveniently located medical care	9%
Difficulty getting time off of work	8%
Lack of transportation to appointments	8%
Competing responsibilities (e.g., childcare, caregiving)	5%
Lack of healthcare plan	5%
Lack of high-speed internet access or Wi-Fi at home	3%
Lack of a caregiver/support system to help me	3%
Lack of access to a computer, tablet, or phone	3%
Other	1%

#### Logistical challenges in accessing healthcare in past 12 months

Patients of color were more likely to experience logistical challenges than white patients—57% vs. 45%, respectively. Three-quarters (76%) of Native American or Pacific Islander patients and 61% of Hispanic patients faced any logistical barriers.

A similar proportion (77%) of patients in the LGBTQIA+ community reported logistical challenges, compared to less than half (47%) of non-LGBTQIA+ patients.

Patients who live in urban or inner-city areas were more likely to experience logistical barriers (54%) compared to 46% of people who live in rural areas and 47% of suburban patients.



#### 2024 STATE OF PATIENT ACCESS FINDINGS Overall access to care



#### Help wanted

Half (52%) of patients said they would like some sort of help related to accessing the healthcare they need. Specifically, they would like help scheduling appointments (16%), finding specialists (15%), coordinating care across multiple HCPs (15%), and learning more about their condition(s) in general (15%). Nearly as many reported wanting help finding resources to pay for medications (14%), ways to more easily access healthcare services (12%), and transportation assistance (11%).

Patients want more help finding specialists, coordinating care, and learning more about their condition.

#### Patients' report on what they need help with to better access healthcare



#### 2024 STATE OF PATIENT ACCESS FINDINGS Overall access to care



HCPs try to help patients overcome barriers to care, with many reporting that they often make referrals to the resources patients say they would appreciate. Some of the most common resources HCPs referred patients to included mental health resources (84% PCPs, 74% NP/PAs, 80% RNs), patient health education tools (57%, 68%, 79%, respectively), nutrition and wellness support programs (70%, 72%, 69%, respectively), and care coordinators or nurse navigators (63%, 61%, 81%, respectively).



#### HCP referrals given to patients in past 12 months

PCPs NP/PAs Nurses

#### **Overall access to care**



Despite the availability of and referrals to these supportive services, relatively few patients take advantage of the help they say they want. Just under half (47%) of patients reported using some type of resource for support with their chronic health condition(s) in the past 12 months. Notably, only 7% of patients reported taking advantage of care coordinators or nurse navigators, despite 15% reportedly wanting help coordinating care across the multiple HCPs they see.

## **47%** of patients reported using some type of resource for support with their chronic health condition(s).

Types of resources patients used in the past 12 months



Half or more HCPs said they would be more likely to refer patients to resources if those resources were part of standard protocols A large majority of HCPs said they wish they knew more about available resources that they could offer to their patients with chronic health conditions (88% PCPs, 87% NP/PAs, 87% RNs). Half or more HCPs surveyed said they would be more likely to refer patients to resources if those resources were part of standard protocols (59% PCPs, 64% NP/PAs, 56% RNs), if another HCP recommended the resource (54%, 56%, 66%, respectively), or if they heard from other patients that the resource was useful (52%, 58%, 50%, respectively).

#### **Overall access to care**



#### Access challenges due to patient characteristics

Many patients perceived that their personal characteristics—such as their income, insurance status, age, location, race or ethnicity, disability status, or employment status—have negatively impacted getting the best possible healthcare. Nearly two in five (38%) patients reported feeling that some aspect of their identity had negatively impacted their ability to get the best possible care.

## **Nearly 1 in 4 patients** felt their income or health insurance most negatively impacted their access to care.



#### Aspects patients believe have negatively impacted their healthcare

Certain patient populations were more likely to feel that aspects of their identity negatively impacted their ability to get the best possible healthcare. For example, 54% of patients of color had this experience, compared with 32% of white patients. Specifically, 25% of Black patients identified their race as a factor in their negative experiences accessing care. By comparison, just 2% of white patients said the same.

Similarly, 27% of Gen Z (people aged 18 to 26) said their age had a negative impact (vs. 9% overall) and 23% of people earning less than \$50,000 per year felt their income affected their ability to access quality care (vs. 16% of all patients). Among LGBTQIA+ patients, 17% cited their gender identity and 14% their sexual orientation as factors that negatively impacted their ability to get the best possible healthcare.

A root cause of perceived bias may be insufficient diversity among HCPs. A majority of HCPs (57% of PCPs, 57% of NP/PAs, and 58% of RNs) agree that there is not enough diversity among HCPs to properly relate to their diverse patients.

### Relationship with Healthcare Professionals

Patients' *Relationship with Healthcare Professionals* in the 2024 *State of Patient Access Scorecard* earned an overall score of "B." To calculate the grade, we included questions about patients' interactions with HCPs that prevented them from getting the care they needed, such as feeling that their HCP is critical of their habits (8%), feeling misunderstood (7%) or intimidated (4%) by their HCP, and finding it difficult to communicate with their HCP due to language barriers (4%). The questions comprising this score also included patients' general degree of trust in HCPs, specific trust that their HCP has their best interests in mind when making healthcare decisions, and their perception that their HCP sees them as a partner in care.



### Health disparities in action

The relatively positive assessment of HCP relationships was not universal. The LGBTQIA+ community rated this composite measure as a "C," and Gen Z and Millennial patients gave it a "C+."

	Total	Race/Ethnicity					Gender/Gender Identity		Generation		Income
		Patients of Color	Black/ African American Patients	Hispanic Patients	Asian Patients	Native American/ Pacific Islander Patients	LGBTQIA+ Patients	Female Patients	Gen Z Patients (ages 18-26)	Millennial Patients (ages 27- 42)	Lower Income Patients (<\$50K)
Relationship with Healthcare Professionals	В	В-	B-	B-	B-	В	с	В	C+	C+	B-



#### 2024 STATE OF PATIENT ACCESS FINDINGS Relationship with healthcare professionals



#### **Using HCP services**

Most (81%) patients reported seeing a PCP in the past 12 months, including 63% who said they had seen a PCP specifically for their chronic health condition(s). More than half (53%) had seen a specialist in the last year, with 41% seeing a specialist specifically for their chronic condition(s). Fewer (18%) had seen a mental health professional.

### **Nearly one in ten (7%)** had not seen any HCP in the past 12 months specifically for treatment of their chronic health condition(s).



#### Types of HCPs seen in past 12 months specifically for treatment of chronic health condition (among those who have seen an HCP in past 12 months)



#### 2024 STATE OF PATIENT ACCESS FINDINGS Relationship with healthcare professionals



#### Trust in HCPs

The vast majority of patients reported high degrees of trust in their HCPs. Specifically, 91% said they strongly or somewhat agree that their HCP has their best interests in mind when making healthcare decisions. Similar percentages agreed that their HCP views them as a partner in their treatment plan (88%) and that their HCP stays current in prescriptions and other treatments for their condition(s) (92%). Almost all patients reported that they trust their PCP (96%), specialist (95%), nurse (94%), NP/PA (94%), and pharmacist (94%). Additionally, only three in ten (30%) viewed artificial intelligence (AI) as a trustworthy source for needed medical care and services.

Most adults trust their HCPs, yet nearly 1 in 3 cite issues preventing effective partnerships.



(% Very/Somewhat Trustworthy)



#### 2024 STATE OF PATIENT ACCESS FINDINGS Relationship with healthcare professionals



#### HCP interaction challenges

Despite high levels of trust in HCPs, 28% of patients who saw an HCP in the past 12 months pointed to some type of interaction with an HCP as a barrier that prevented them from getting the healthcare they needed. Specifically, 11% said they felt their HCP did not take their concerns seriously. Some felt their HCP was critical of their habits (8%), did not understand them (7%), or made them feel uncomfortable (7%) or intimidated (4%). Others faced language barriers (4%). Diving into specific subgroups, 40% of patients of color experienced an interaction-related obstacle in trying to access care, nearly double the rate of white patients (23%). Nearly one-third (35%) of urban/inner-city patients experienced interaction-related challenges, compared with 26% of suburban patients and 23% of patients living in rural areas.

#### Patient's interactions with HCPs that prevented getting healthcare

(among patients who have seen HCP within past 12 months)

### **28%** reported some type of interaction with an HCP as a barrier that prevented them from getting the healthcare they needed.

I feel like my healthcare professional <b>does not take</b> <b>my concerns seriously</b>	fessional <b>does not take</b> professional is		l am <b>uncomfortable</b> <b>talking</b> with my healthcare professional
11%	8%	7%	7%
<b>I feel intimidated</b> by my healthcare professional	My healthcare professional and I have difficulty understanding one another due to <b>cultural differences</b>	My healthcare professional and I have difficulty understanding one another due to <b>language barriers</b>	Other
4%	4%	4%	1%

#### HCP views on patient communication

Interaction challenges may suppress patients' willingness to communicate with their providers, a point of disappointment for HCPs. Only half of PCPs (50%), NP/PAs (50%), and nurses (52%) said their patients speak up during appointments. PCPs said they wished their patients would communicate with them more openly (70%) but pointed to lack of time during appointments as an obstacle to building better relationships with patients (88%). Almost all (94%) of RNs said they wished there was more they could do to encourage patients to open up during appointments, as did 80% of NP/PAs.

### Affordability of Prescription Medications

Out-of-pocket drug costs get a lot of attention because they create many obstacles for patients, often with dire consequences. In our analysis, while the overall score for this measure was not terribly low-a "B-"-many patients reported significant challenges accessing needed medications. Our composite measure of prescription drug affordability incorporated questions that addressed how many patients viewed their prescriptions as unaffordable, patients' challenges paying for medications, anxiety about the future cost of their prescriptions, financial actions taken to afford medications, how many were unable to get prescriptions due to high out-of-pocket costs, actions they took as result of not getting their medications, the health implications for not getting needed medications, and how many would like help finding resources to pay for prescriptions.

#### Health disparities in action

Despite the overall grade of "B-" some groups had worse ratings for prescription affordability. Hispanic, Native American or Pacific Islander, LGBTQIA+, Gen Z, and Millennial patients all gave this metric an overall grade of "C."

The cost of prescription medications is particularly relevant to this patient population given their chronic health conditions. The mean number of prescriptions patients reported they are currently being prescribed for their chronic health condition is four, with 89% taking at least one prescription medication and 28% taking five or more.



## Adults with chronic conditions are prescribed an average of **four prescription medications.**

Number of prescription medications patients currently take





#### 2024 STATE OF PATIENT ACCESS FINDINGS Affordability of prescription medications



#### Cost obstacles

Patients currently prescribed at least one medication for their chronic health condition reported a mean out-of-pocket spending on medications of \$366 in the past 12 months. One-fifth (21%) reported that they spent more than \$500 on prescriptions in that period.

One in five (22%) patients with this expense said that their prescription medication costs were not at all or not very affordable in the past year. These costs created hardships for many. Among patients currently prescribed at least one medication, nearly one-quarter (22%) said that affording their prescription(s) in the past 12 months has been very or somewhat difficult. Additionally, one-third (33%) said they are very or somewhat worried about their ability to pay for prescription medication costs in the next 12 months.

### 1 in 5 patients taking medications find it difficult to afford them.



30% Somewhat easy Very easy

Percentages may not add up to 100% due to weighting and/or computer rounding

on prescription medications in the past 12 months

(\$613; \$548 on average respectively).



#### Patients' overall out-of-pocket costs for prescription medications in past 12 months

(among patients taking at least one prescription)

#### 2024 STATE OF PATIENT ACCESS FINDINGS Affordability of prescription medications



Prescription costs also made it difficult for many patients to get the medication they needed; 17% said they needed a prescription in the past year that they did not get because of high out-of-pocket costs. This figure was even higher for patients of color (22% vs. 14% of white patients) and for people with certain conditions: 30% for people with immunological conditions and approximately onequarter for patients with chronic pain syndrome (26%), endocrine disorders (24%), and mental health conditions (23%).

### 17% of patients reported needing a prescription in the past 12 months but did not get due to high out-of-pocket cost.



PCPs said that 21% of their patients, on average, have not filled a prescription because of high outof-pocket costs, compared with 25% reported by NP/PAs, and 32% by RNs. Despite patient concerns about prescription drug costs, the majority of HCPs who can prescribe-including 65% of PCPs and 74% of NP/PAs-reported that their first consideration when making prescribing decisions for their patients is the effectiveness of the prescription medications. Just 28% of PCPs said they consider the affordability for their patient as their top consideration when

#### Proportion of patients who did not fill a medication because of high out-of-pocket costs

	Mean	Median
PCPs	21%	20%
NP/PAs	25%	20%
Nurses	32%	25%

prescribing medications, compared to 19% of NP/PAs.

#### Affordability of prescription medications



#### Financial actions taken to offset prescription cost hardships

More than one-third (36%) of patients taking prescription medications said that they had taken at least one financial action to offset the hardships posed by prescription drug costs. For example, 15% said they had reduced spending in other areas to make room in their budget for prescriptions. Another 12% explored discount saving apps, and about one in ten used other means of paying for their prescriptions, such as taking on credit card debt (11%), delaying payment of other bills (10%), dipping into other savings (9%), or dipping into retirement savings (5%).

A small percentage (6%) of these patients said they sought financial assistance to afford their prescription medications. Of those, 61% asked friends or family for financial help, 30% looked to the drug manufacturer for assistance, and approximately one-quarter sought help from a patient advocacy group (24%) or an independent charitable foundation (23%). Another 16% turned to their place of worship and 15% tried crowdsourcing.

Patients of color taking at least one medication were more likely to take financial actions to afford their medications—46% had taken some action compared with 31% of white patients.

HCPs reported trying to help patients with referrals to financial resource options. The majority of HCPs (81% of PCPs, 85% of NP/PAs, and 61% of RNs) said they referred patients to the pharmaceutical manufacturer for help paying for their prescription. The next most common resources that HCPs referred patients to were patient advocacy groups (30% of PCPs, 44% of NP/PAs, and 60% of RNs) and independent charitable foundations (28% of PCPs, 30% of NP/PAs, and 46% of RNs).

## **36%** reported that they have taken at least one financial action to offset the hardships posed by prescription drug costs.

Actions taken to afford needed prescription medications (among patients taking at least one prescription)							
Reduced my spending in other areas of my budget <b>15%</b>	Explored discount saving apps <b>12%</b>	Took on credit card debt <b>11%</b>	Delayed paying other bills <b>10%</b>	Dipped into other savings <b>9%</b>			
Sought financial assistance <b>6%</b>	Dipped into retirement savings <b>5%</b>	Filed for bankruptcy <b>2%</b>	Took out a second mortgage <b>2%</b>	Other <b>1%</b>			
# 2024 STATE OF PATIENT ACCESS FINDINGS Affordability of prescription medications



# Patient responses to unaffordable prescription costs

Among patients who said they could not get a prescription due to high out-of-pocket costs, 94% took action as a result. More than half (55%) said they simply did not fill a prescription, whereas 26% said they rationed their medicine and 18% said they cut pills in half. Another quarter (24%) said they stopped taking the medication altogether and one in ten (10%) said they used someone else's prescription medicine. Some patients in this predicament were proactive: 30% asked their HCP to prescribe them a more affordable medication and 22% said they asked their HCP for free samples of their prescription medication.



# Patients' actions taken because they could not get medication

(among patients who did not get medication because of cost)

55%	Did not fill a prescription
30%	Asked my healthcare professional to prescribe a more affordable prescription medication
26%	Rationed prescription medication
24%	Stopped taking prescription medication altogether
22%	Asked my healthcare professional for free samples of the prescription medication
18%	Cut pills in half
10%	Used someone else's prescription medication
7%	Asked my healthcare professional about participating in a clinical trial
3%	Other
6%	None

# 2024 STATE OF PATIENT ACCESS FINDINGS Affordability of prescription medications



# Negative impacts of prescription affordability challenges

Cost barriers had an impact on patients' ability to get medication(s): 14% of patients who could not get their needed medication because of cost said they had to change their treatment plan and as many said they delayed the start of treatment as a result of not getting their prescriptions. Not filling prescriptions because of high costs also impacted care-seeking behaviors: 13% said they had more unplanned HCP visits, 11% reported going to the emergency room or urgent care facility, 10% had to have more tests than they otherwise would have, and 8% said they were prescribed additional medications due to the impact on their health.

Most (79%) patients who said they did not get a prescription medication due to cost experienced some negative physical impacts as well. One-third (34%) said that their physical and/or mental health had suffered, and 31% said their daily life had been impacted.

# **79%** of patients who said they did not get a prescription medication due to cost experienced at least one negative impact.

(among patients who did not get medication because of cost)

34%	My physical health suffered	11%	l ended up visiting the emergency room/urgent care
34%	My mental health suffered	10%	I had to have testing that I otherwise may not have needed
31%	My day-to-day life was impacted	8%	I was prescribed more prescription medications than before due to the impact on my health
14%	I had to change my treatment plan	8%	My childcare duties were impacted
14%	It delayed the start of my treatment	1%	Other
13%	l scheduled unplanned visits with my healthcare professional		

# 2024 STATE OF PATIENT ACCESS FINDINGS

# Access to Treatment through Healthcare Plans

Access to Treatment through Healthcare Plans earned a "D-" overall. Specific questions that contributed to this score included patient challenges accessing medication through their health insurance, lack of insurance deductible affordability, financial worries about future affordability of deductibles, confusion about health plan details, and concern that their health plan would make access to medications more difficult in the coming years.

Insurance plans can provide essential financial protection from healthcare costs, but for patients with coverage who take prescription medications, insurers also create obstacles—both administrative and financial.



# Health disparities in action

While the composite score was a "D-," certain patient segments rated this measure even worse. Hispanic, Native American or Pacific Islander, LGBTQIA+, Gen Z, Millennial, and patients with lower incomes all gave this measure a failing grade of "F."



**49% of patients** reported facing some form of insurance related barrier to accessing prescription medications. Nearly half (49%) of patients reported facing some form of insurance-related barrier to accessing their prescription medication(s), such as prior authorization needed (19%), prescription medication not covered by healthcare plan (17%), or high out-of-pocket costs (15%). These rules make accessing drugs difficult, and these costs erode the financial value of insurance. Patients with certain conditions reported insurancerelated challenges to medication access at even higher rates. Specifically, 65% of patients with immunological conditions faced insurance-related barriers to accessing their prescription medications, as did 60% of patients with chronic pain syndrome and 59% of patients with a gastrointestinal condition.

# 2024 STATE OF PATIENT ACCESS FINDINGS Access to treatment through healthcare plans



# Affordability

Nearly one-third (31%) of patients who had this expense said that their healthcare plan deductible was not at all or not very affordable in the past year. Deductibles also served as a source of financial anxiety, with 36% of patients who had deductible expenses reporting that they were very or somewhat worried about their ability to afford them in the next 12 months. Even among patients with insurance coverage, many faced specific challenges getting their prescription medications due to high out-of-pocket costs (15%) and high deductibles (13%).

# Fear of future access challenges

Patients' outlook for their future access to medications was not good. Nearly three in five (58%) patients said they worry that over the next five years, their health plan will make it more difficult for them to access their needed prescriptions. Patients with private health insurance were more likely to strongly agree with this concern (18%) compared to patients with public health insurance (12%).

# Healthcare plan related challenges reported by patients in accessing their prescribed medications

19%	Prior authorization needed
17%	Prescription medication not covered by healthcare plan
15%	High out-of-pocket costs
13%	High deductible
10%	Needed to try a different/alternative prescription medication before getting coverage for the one my healthcare professional prescribed for me
9%	Prescription medication considered "non-essential" by healthcare plan
7%	Prescription medication considered "unnecessary" by healthcare plan
6%	Patient assistance
1%	Other

**Nearly three in five (58%) patients** said they worry that over the next five years, their health plan will make it more difficult for them to access their needed prescriptions.



Patients with private health insurance



18%

# 2024 STATE OF PATIENT ACCESS FINDINGS Access to treatment through healthcare plans

# Administrative hurdles

Health insurers often use administrative rules to limit access to specific services and treatments. Ostensibly, these practices are designed to ensure that patients get the most appropriate care. In effect, they often cause burdens for people trying to access services or medications.

In the survey, nearly one in five (19%) patients who have a healthcare plan and take prescription medication(s) said their insurance plan required them to get prior authorization for their prescription medication(s). 10% said that their insurer required them to try a lower cost/ alternative prescription medication(s) before they would provide coverage for prescribed treatment, a practice called step therapy.

Some healthcare plans simply did not cover patients' prescription medication(s), a barrier reported by 17% of insured patients who take prescription medication. Similarly, nearly one in ten of these patients said their health plan considered their medication "non-essential" (9%) and had been told by their health plan that their medication was "unnecessary" (7%).

# <image>

# **Insurance literacy**

More than half (53%) of patients agreed that trying to understand the details of their healthcare plan is nearly impossible. Specific aspects of health insurance were particularly confusing or unfamiliar to patients with chronic conditions. Many patients said they had never heard of certain insurance concepts such as copay accumulators (66%), copay maximizers (65%), and alternative funding programs (56%). Less than one-quarter (22%) said they were extremely, very, or somewhat familiar with these concepts.

When asked how confident HCPs are about their ability to explain these concepts to their patients with chronic health conditions, PCPs were the least confident. Just 25% of PCPs said they felt very or somewhat confident in their ability to explain copay accumulators, 27% said the same of copay maximizers, and 36% were confident about explaining alternative funding programs. Nurses expressed the most confidence, with 46%, 44%, and 70% saying they could explain copay accumulators, copay maximizers, and alternative funding programs, respectively.

# 2024 STATE OF PATIENT ACCESS FINDINGS

# Access to treatment through healthcare plans

# **HCP frustrations**

A majority of HCPs expressed frustration dealing with healthcare plans to get their patients the prescription medication(s) they need, including 92% of PCPs and NP/PAs, and 90% of RNs. Similarly, more than three in four HCPs (77% of PCPs, 79% of NP/PAs, and 83% of RNs) said that their patients do not receive their medications in a timely way because of complexities within their healthcare plan.

Insurance barriers for patients also cause direct burdens on HCPs: 90% of PCPs, 92% of NP/PAs, and 82% of RNs strongly or somewhat agreed that dealing with healthcare plans to help their patients get the prescription(s) they need takes a lot of their or their staff's time.

Nearly two-thirds (64%) of PCPs said at least every week they have to submit requests to healthcare plans for approval of medications they prescribe to their patients; nearly one-quarter (23%) of PCPs said they do so every day. These figures were lower for other HCPs—58% of NP/PAs and 58% of RNs file these requests at least weekly.

# Percentage of HCPs who agree with the following statements:



"It is very frustrating dealing with healthcare plans to get my patients the prescription medication that they need." "Many of my patients do not receive their medications in a timely fashion due to complexities within their healthcare plans."





# 2024 STATE OF PATIENT ACCESS FINDINGS Financial Toxicity



Financial toxicity is commonly defined as the harmful effects healthcare costs can have on a patient's life or well-being. In our study, financial toxicity is specifically defined as "the emotional, mental, and physically debilitating and often life-threatening—financial side effects and burdens associated with treatment for your chronic condition(s)." To capture the extent of this phenomenon, our *Financial Toxicity* index gives full weight to the survey question, "To what extent does 'financial toxicity' impact you?" Nearly one-quarter (23%) of patients said that financial toxicity impacted them a great deal or a lot.

# Health disparities in action

This measure had the most variation across patient groups. People of color overall gave it a "C-," though there was variation across racial and ethnic groups: Hispanic patients gave Financial Toxicity an "F" and Black patients gave it a "D." LGBTQIA+ and Millennial patients also gave this measure an "F." Gen Z patients and patients with lower income (less than \$50K) incomes gave *Financial Toxicity* a "D-" and female patients gave it a "D+."

	Total	Race/Ethnicity					Gender/Gen	der Identity	Generation		Income
		Patients of Color	Black/ African American Patients	Hispanic Patients	Asian Patients	Native American/ Pacific Islander Patients	LGBTQIA+ Patients	Female Patients	Gen Z Patients (ages 18-26)	Millennial Patients (ages 27- 42)	Lower Income Patients (<\$50K)
<b>Financial Toxicity</b>	C-	D-	D	F	C-	D-	F	D+	D-	F	D-

Some patients were more likely to experience financial toxicity than others. For example, 31% of patients of color said financial toxicity impacts them a great deal or a lot compared with 20% of white patients. Hispanic patients had the highest rates of financial toxicity (37%), followed by Native American or Pacific Islander patients (29%) and Black patients (27%). About one-quarter (27%) of urban and inner-city patients faced high levels of financial toxicity compared with 23% of patients living in suburbs and 21% of patients in rural areas. One-third (33%) of patients in households earning less than \$50,000 annually experienced a great deal or a lot of financial toxicity, compared with 19% of patients in households with annual earnings greater than \$50,000.

# 2024 STATE OF PATIENT ACCESS FINDINGS **Financial toxicity**



# Healthcare affordability

Financial toxicity is related to overall healthcare affordability, or lack thereof. Healthcare costs are among patients' top affordability challenges. When asked about the affordability of different types of expenses, 52% said that unexpected medical bills were not very or not at all affordable for them in the past 12 months. These unexpected medical bills were second only to daycare/childcare costs (55%) and ranked higher than rent/ mortgage (35%) and monthly utilities (34%). Another 41% said they had had difficulty affording a surgery or medical procedure that they needed in the last year.

Nearly three in five patients of color say they would only be able to afford an unexpected medical bill less than \$500.

# 1 in 2 patients say that unexpected medical bills were not affordable in the past 12 months, and a similar proportion worry about this for next year.



# Worry about affordability in next 12 months



Very/somewhat worried (net)

# 2024 STATE OF PATIENT ACCESS FINDINGS Financial toxicity



# Outstanding and unexpected medical bills

Nearly one-quarter (22%) of patients reported having outstanding medical bills they were not sure how to pay. Of these patients, 58% said they have \$500 or more in outstanding bills they were not sure how to pay. The average amount patients reported not knowing how to pay was nearly \$5,000 (\$4,788 on average).

Looking ahead, nearly half (46%) of patients reported that they were very or somewhat worried about being able to afford unexpected medical bills that could arise in the coming year. More than one-third (35%) said they were worried about being able to afford a surgery or medical procedure that they might need in the coming year.

Related, 49% of patients said that if they did get an unexpected medical bill, their family would only be able to afford less than \$500. Patients of color were more likely than white patients to say that they would only be able to absorb an unexpected medical bill that was less than \$500–59% vs. 45%, respectively. More than two-thirds (69%) of LGBTQIA+ patients said they would only be able to afford an unexpected medical bill under \$500, compared with 48% of non-LGBTQIA+ patients.

# Unaffordability of an unexpected medical bill of any amount in the past 12 months





# Ability to afford unexpected medical bills of varying amounts

# Conclusion



# Conclusion

Living with a chronic health condition in the United States is not easy. Living with multiple conditions, as many people do, is even more challenging. Add to the strain of managing health conditions the costs and access challenges many face in the United States, and it can be downright daunting to be a patient. Further compounding the challenges is the unfortunate reality that patients from historically marginalized communities face additional, unique, and overlapping barriers to the care they need.

Many chronic conditions require patients to take long-term medications. Timely and affordable access to those treatments is essential to one's health and well-being. The *2024 State of Patient Access* survey highlights challenges people in the U.S. face accessing the care they need. These challenges are exacerbated in many instances, based on one's race and ethnicity, gender identity, sexual orientation, age, and other demographic characteristics.

Different patients face different nuanced challenges, with some focused on financial barriers and others hampered by the sense that aspects of their identity prevent them from getting the best possible care. Despite these differences in the nature of barriers different groups face, adults with chronic health conditions share a basic set of common challenges.

# Our findings indicate that:

- Adults with chronic conditions do not give access to medical care in the U.S. high marks.
- Americans struggle to afford the care they need, including prescription medications.
- Socioeconomic factors impact one's ability to access needed care.
- Inability to access needed treatment, such as prescription medications, negatively impacts the physical and mental health of adults living with chronic conditions.
- Adults with chronic conditions and HCPs alike recognize the need to improve communication.
- Adults with chronic conditions and their HCPs cite challenges with healthcare plans that negatively impact access to timely and affordable medication.
- Healthcare plan deductibles are unaffordable for many.
- Adults in the U.S. struggle with understanding health insurance terminology. HCPs cannot always help because they lack confidence in their own ability to explain certain insurance concepts.
- Too many adults with chronic conditions report high financial toxicity levels.

# Conclusion

# These findings point to several key opportunities:

- Exploring legislative and regulatory policy solutions that can improve access to care for adults living with chronic conditions;
- Improving education and outreach efforts to advance health literacy; and
- Improving awareness of and access to needed financial assistance.

Effective solutions to improve access to care must be designed based on a keen understanding of the nuanced differences between demographic groups. As stakeholder groups work together to improve access to care for adults with chronic conditions, we hope to see improvements in how adults with chronic conditions perceive and experience access to needed care and treatment, year over year.



# Appendix



# APPENDIX Patient survey methods

# **Method statement**

The research was conducted online in the United States by The Harris Poll on behalf of the PAN Foundation among 2,502 adults age 18+ who reside in the U.S. and have by diagnosed by a healthcare professional with a chronic health condition (including 2,367 completes from the general population and race/ethnicity oversamples and 135 completes from the LGBTQIA+ oversample). The survey was conducted August 10 – September 6, 2023 in both English and Spanish languages.

Data for the General Population (Gen Pop) sample and Hispanic, Black/African American, Asian, and Native Hawaiian/Other Pacific Islander/American Indian/Alaskan Native race/ethnicity subgroups are each weighted individually where necessary by: age, gender, race/ethnicity (total Gen Pop data only), Asian subgroup (Asian data only), Native subgroup (Native Hawaiian/Other Pacific Islander/ American Indian/Alaskan Native data only), region, education, marital status, household size, employment, household income, aggregated language proficiency (Hispanic only), LGBTQIA+ status (excluding Native Hawaiian/Other Pacific Islander/American Indian/Alaskan Native), and propensity to be online to bring them in line with their actual proportions in the population. A post-weight was then applied to combine all data and weighted where necessary by race/ ethnicity. Separately, due to overlap with the other samples, data for the LGBTQIA+ sample are weighted where necessary by age, gender, education, race/ethnicity, sexual orientation, region, household size, marital status, and propensity to be online to bring them in line with their actual proportions in the population.

Respondents for this survey were selected from among those who have agreed to participate in our surveys. The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within + the below percentage points using a 95% confidence level:

Total: + 2.9 percentage points

•

- Hispanic: + 7.8 percentage points
- Black/African American: + 6.0 percentage points
- Asian: + 9.6 percentage points
- Native Hawaiian/Other Pacific Islander/American Indian/Alaskan Native: + 13.8 percentage points
- LGBTQIA+: + 7.2 percentage points

This credible interval will be wider among subsets of the surveyed population of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.

# APPENDIX Patient demographics

# Patients' reporting of chronic conditions and ranking of conditions with the greatest negative impact

Patients Report of Chronic Conditions

	2023 (A)				
Cardiovascular condition	35%				
Mental health condition	33%				
Gastrointestinal condition	22%				
Musculoskeletal condition	21%				
Chronic pain syndrome	19%				
Chronic respiratory condition	17%				
Endocrine disorder	14%				
Thyroid disorder	13%				
Cancer	13%				
Other chronic health condition	9%				
Ophthalmologic condition	5%				
Immunological condition	5%				
Autoimmune disease	5%				
Renal (Kidney) condition	4%				
Neurological condition	3%				
Chronic liver disease	3%				
Infectious diseases	2%				
Genetic disorder	1%				
Endocrine diseases	1%				
Hematological condition	1%				
Other rare disease	1%				
Metabolic disorders	0%				

Condition that has Greatest Negative Impact (among patients with more than one Chronic Condition)

2023 (A) 13% 18% 9% 10% 12% 9% 6% 2% 5% 4% 2% 5% 4% 1% 3% 1% 3% 1% 3% 1% 3% 1% 1% 3% 1% 1% 3% 1% 0% 0% 0%	
18%         9%         10%         12%         9%         6%         2%         5%         4%         1%         3%         1%         3%         1%         3%         1%         0%         0%         0%         0%         0%         0%	
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10%         12%         9%         6%         2%         5%         4%         1%         3%         1%         3%         1%         3%         1%         0%         0%         0%         0%         0%	18%
12% 9% 6% 2% 5% 4% 1% 3% 1% 1% 3% 1% 1% 1% 1% 1% 1% 0% 0% 0%	9%
9% 6% 2% 5% 4% 1% 3% 1% 3% 1% 3% 1% 1% 1% 1% 0% 0% 0%	10%
6% 2% 5% 4% 1% 3% 1% 1% 3% 1% 1% 1% 1% 0% 0% 0%	12%
2% 5% 4% 1% 3% 1% 1% 3% 1% 1% 1% 1% 0% 0% 0%	9%
5% 4% 1% 3% 1% 1% 3% 1% 1% 1% 1% 0% 0% 0%	6%
4% 1% 3% 1% 1% 3% 1% 1% 1% 0% 0% 0%	2%
1% 3% 1% 1% 3% 1% 1% 1% 1% 0% 0% 0%	5%
3% 1% 1% 3% 1% 1% 1% 0% 0% 0%	4%
1% 1% 3% 1% 1% 1% 0% 0% 0%	1%
1% 3% 1% 1% 1% 0% 0% 0%	3%
3% 1% 1% 1% 0% 0% 0%	1%
1% 1% 1% 0% 0% 0%	1%
1% 1% 0% 0% 0%	3%
1% 0% 0% 0%	1%
0% 0% 0%	1%
0% 0%	1%
0%	0%
	0%
0%	0%
	0%

# APPENDIX Healthcare professional survey

# Method statement

The research was conducted online in the United States by The Harris Poll on behalf of the PAN Foundation among 251 primary care physicians duly licensed and specializing in family practice, general practice, internal medicine, or geriatric medicine ("PCP"), 150 licensed nurse practitioners and physician associates/physician assistants ("NP/PA"), and 100 registered nurses ("RNs") aged 18+ practicing in the U.S. for at least a year and see at least 10 adult patients with a chronic health condition per month. The survey was conducted August 10 – 28, 2023.

To bring them in line with their actual proportions in the population, PCP data are weighted where necessary by age, gender, and specialty; NP/PA data are weighted where necessary by age, gender, education, race/ethnicity, region, employment status, and profession; RN data are weighted where necessary by age, gender, education, race/ethnicity, region, and employment status.

Respondents for this survey were selected from among those who have agreed to participate in our surveys. The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within + 6.5 percentage points for PCPs, + 8.8 percentage points for NP/PAs, and + 12.3 percentage points for RNs using a 95% confidence level. This credible interval will be wider among subsets of the surveyed population of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.

# APPENDIX Healthcare professional survey

# Healthcare professional demographics

# PCPs



### NP/PAs

Gender	18+ Patients Seen Prescriptions Written	Employment Status 100% Employed (FT, PT, or Self) 0% All other		Patients Seen Per Week	Patients Healthcare Plans		Patient Population Groups	
	per Month with Chronic Health			$\bigcirc$	35% Commercial healthcare		3% Pediatric	
	Condition (133) (87)			81		plan	23%	Adult
	Mean Mean			Mean	26% Medicare		7% Geriatric	
ПП	Current Occupation	Licensed in State	Educatio		9%	Medicare Advantage	39%	Adult and Geriatric
		Currently Practicing	0%	Less than HS degree	20%	Medicaid	28%	All ages
16% 82% Male Female	62% Nurse Practitioner	100% Yes	0% HS degree to less than 4-yr degree		5% Other		Practice Location Type	
*1% prefer not to answer	38% Physician Associate/Physician Assistant	0% No 10		100% 4-yr college degree or more		Uninsured	79%	Mostly office- or clinic-based
ocation of Practice		Proportion of Patients	Sta	ff Member in Office who	Office/0	Clinic Setting	4%	Mostly hospital- or lab-based
E 249/	50% Suburban	Who Speak Native	can Speak Patients Native				7%	Exclusively hospital- or lab-
A Inner city/Urban		Language Other than English	Lar	nguage? 64% Yes	12%	Solo practice		based
				36% No	40%	Single-specialty partnership or group	3%	Mostly long-term care facility based
Age	Nurse Care Coordinator on Staff	Mean					-	Mostly hospice-based
82% Under 55 43	51% Yes				49%	Multi-specialty partnership or group	7%	Equally hospital-based and
18% 55+ Mea	n 49% No	and the second second				participants of Broad		office/clinic-based
Race	Offer Multidisciplinary Care	Years in Practice	65 6	N			1%	Other
77% White	54% Yes	0-2 years			Ages o	f Patient Population	US Rej	gion of Practice
6% Black	46% No	■ 3-10 years	/		13%	Under 30	21%	Northeast
5% Hispanic	Patients Health Literacy	<ul> <li>11-20 years</li> </ul>	46	12	18%	30-49	22%	Midwest
5% Asian/ Pacific Islander	23% Poor	= 21-30 years		46% Mean	26%	50-64	37%	South
	29% Fair	= 31+ years			26%	65-74	19%	West
	31% Good	- an years			17%	75+		
	17% Excellent						6	

# APPENDIX

# Healthcare professional survey

# Healthcare professional demographics

## Nurses



# APPENDIX 2024 State of Patient Access Scorecard methodology

To create the *State of Patient Access* 2024 Index Scores, we created a composite index to combine various dimensions into a single metric. Composite indices use a variety of survey questions or response options, assigning each a weight. The weights assigned to each question or response option total 100 within each index category.

Individual respondents are then assigned a score between 0-100 based on their responses to each of the included survey questions. The average of respondents' scores yields a composite index score which summarizes the attributes or dimensions within a single metric. We created five such metrics as well as an overall composite score.

# Index Methodology

A Composite Index is an approach used to combine various dimensions into a single metric.





Individual respondents are then assigned a score between 0-100 based on their responses to each of the included survey questions.



The average of respondents' scores yields a composite index score which summarizes each of these attributes or dimensions within a single metric.

# APPENDIX

# Scorecard components

### Overall Access to Care

- **20 Points: Q700** Grade of overall ability to access needed healthcare in past 12 months
- **15 Points: Q705** Overall quality of healthcare received in Past 12 Months (% Poor/Fair)
- **15 Points: Q1300** Quality of healthcare coverage over the past 12 months
- 17 Points: Q1000 Negative impact to care in past 12 months (healthcare plan type, sexual orientation, citizenship status, geographic location, race/ethnicity, spoken language)
- **17 Points: Q1010** Any logistical access challenges to needed care in past 12 months
- **15 Points: Q1025** Desire for help with access related elements of healthcare

### Relationship with Healthcare Professionals

- **35 Points: Q1015** Any HCP interaction-related challenge to needed care in past 12 months
- **30 Points: Q940** Trust in PCPs/Nurses/NP/PAs
- **20 Points: Q1020** Agree that HCP sees them as a partner in treatment plan
- **15 Points: Q1020** Trust that HCP has their best interest in mind when making healthcare decisions

### Affordability of Prescription Medications

- **16 Points: Q1100** Prescription medication costs were not at all/not very affordable in past 12 months
- **10 Points: Q1105** Worried about prescription medication costs in next 12 months
- **16 Points: Q1205** Very/somewhat difficult to pay for prescription medication costs in past 12 months
- **11 Points: Q1225** Took any financial action to afford prescription medication in past 12 months
- **18 Points: Q1215** Could not get prescription medication in past 12 months due to high out of pocket costs
- **14 Points: Q1240** Took any action as a result to not getting medication in the past 12 months
- 14 Points: Q1245 Health implications as a result of inability to get prescription medication in the past 12 months.
- **1 Point: Q1025/6** Desire help with finding resources to afford prescription medication

### Access to Treatment through Healthcare Plans

- **40 Points: Q1220** Medication access challenges due to healthcare plan in past 12 months
- **22 Points: Q1100** Healthcare plan deductibles were not at all/not very affordable in past 12 months
- **14 Points: Q1105** Worried about healthcare plan deductibles in next 12 months
- 12 Points: Q1335 Agree that healthcare plan details are nearly impossible to understand
- **12 Points: Q1335** Agree they are worried about health access getting more difficult in the coming years

### **Financial Toxicity**

 100 Points: Q1110 – Financial toxicity experienced a lot/ great deal due to cost of treatment



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The PAN Foundation helps underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access, affordability, and equity for all.