ALTARUM
HEALTHCARE VALUE HUB

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Illinois Residents Bear Healthcare Affordability Burdens Unequally; Distrust of/Disrespect by Healthcare Providers Lead Some to Delay/Go Without Needed Care

A survey of more than 1,000 Illinois adults conducted from December 23, 2021 to January 2, 2022 revealed that a majority of respondents have experienced one or more healthcare affordability burdens in the past year and over three quarters have serious concerns about their ability to afford healthcare now or in the future, with significant disparities based on race and disability status.

- Overall, **58%** of Illinois respondents experienced one or more healthcare affordability burdens in the past 12 months and **80%** worry about affording some aspect of healthcare now or in the future.
- Respondents living in households with a person with a disability more frequently reported affordability burdens compared to respondents without a disabled household member, including: rationing medication due to cost (**45%** vs **19%**); delaying or going without care due to cost (**72%** vs **40%**); and going into medical debt, depleting savings or sacrificing basic needs due to medical bills (**55%** vs **24%**).
- Forty-one percent of Black/African American respondents and **36%** of Hispanic/Latinx respondents skipped needed medical care due to distrust of or feeling disrespected by healthcare providers, compared to **20%** of white respondents.
- Sixty-one percent of all respondents think that people are treated unfairly based on their race or ethnic background somewhat or very often in the U.S. healthcare system.

Differences in Affordability Burdens and Concerns

Race & Ethnicity

Racial disparities in healthcare are well-documented and affordability issues impact access to care and financial burdens for communities of color, particularly Black and Hispanic/Latinx communities.[1,2] In Illinois, Black/African American and Hispanic/Latinx respondents reported higher rates of affordability burdens than white respondents, including higher rates of rationing medication due to cost; delaying or going without care due to cost; and incurring medical debt, depleting savings or sacrificing basic needs (like food, heat and housing) due to medical bills (see Table 1).

In addition to rationing medication, Hispanic/Latinx and Black/African American respondents more frequently reported difficulty getting mental health treatment and delaying/going without medical assistive devices due to cost, compared to white respondents (see Figure 1). Hispanic/Latinx respondents also more frequently avoided going to the doctor or having a procedure done due to cost than respondents identifying with other racial/ethnic groups. Respondents across all three racial/ethnic groups reported similar rates of going without needed dental care and problems getting addiction treatment due to cost.[3]

Table 1

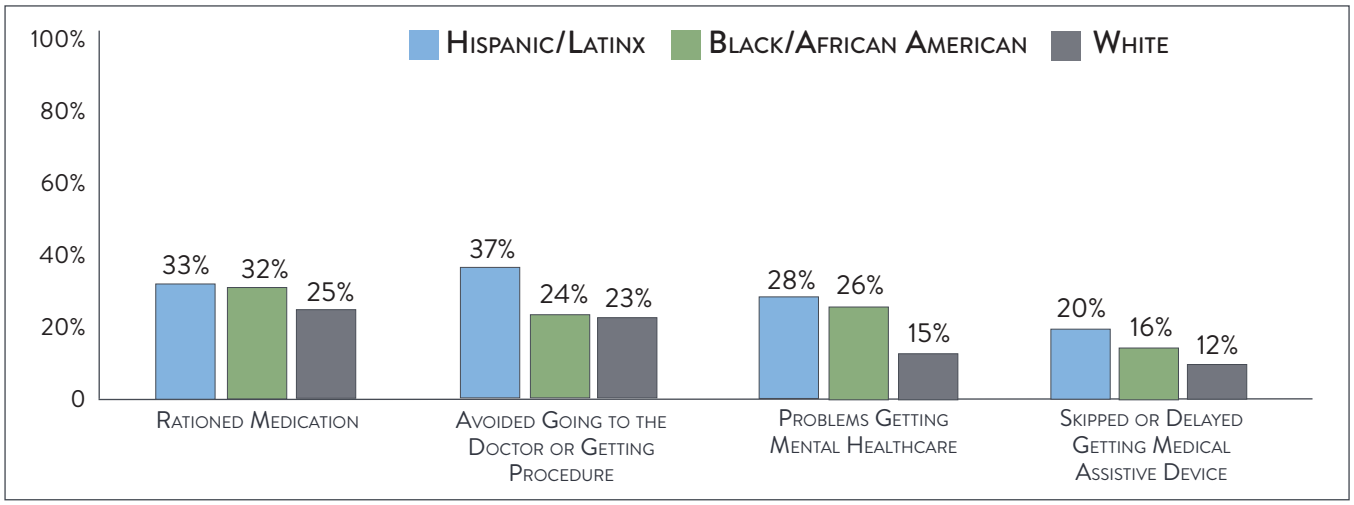
Percent Who Experienced Healthcare Affordability Burdens, by Race/Ethnicity

	Black/African American	Hispanic/Latinx	White
Any Healthcare Affordability Burden	67%	67%	54%
Any Healthcare Affordability Worry	80%	83%	79%
Rationed Medication Due to Cost	32%	33%	25%
Delayed/Went Without Care Due to Cost	54%	54%	47%
Incurred Medical Debt, Depleted Savings and/or Sacrificed Basic Needs due to Medical Bills	49%	46%	29%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

Figure 1

Percent Who Went Without Select Types of Care Due to Cost, by Race/Ethnicity



Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

* Note: Due to small sample sizes, we could not produce reliable statistics exclusively for individuals who identify as American Indian or Native Alaskan (38 respondents), Asian (34 respondents), or Native Hawaiian or other Pacific Islander (3 respondents). We regret that we were unable to supply additional information on healthcare affordability issues in these communities.

Income

The survey also revealed differences in how Illinois respondents experience healthcare affordability burdens by income. Unsurprisingly, respondents at the lowest end of the income spectrum most frequently reported affordability burdens, with almost 7 in 10 (**67%**) of those with household incomes of less than $50,000 per year struggling to afford healthcare in the past 12 months (see Table 2). Still, roughly half of respondents living in middle- and high-income households reported struggling to afford some aspect of coverage or care, demonstrating that affordability problems go far up the income ladder. At least **70%** of respondents in each income group reported being worried about affording healthcare either now or in the future.

Respondents living in lower-income households also more frequently reported rationing care due to cost. Over half (**57%**) of lower-income earners reported delaying or going without at least one healthcare service or treatment due to cost in the past year, compared to slightly less than half

Table 2

Percent Who Experienced Healthcare Affordability Burdens, by Income

	Less than $50K	$50K-$75K	$75K-$100K	More than $100K
Any Healthcare Affordability Burden	67%	56%	56%	48%
Any Healthcare Affordability Worry	85%	85%	81%	70%
Rationed Medication Due to Cost	31%	24%	28%	23%
Delayed/Went Without Care Due to Cost	57%	47%	48%	41%
Incurred Medical Debt, Depleted Savings and/or Sacrificed Basic Needs due to Medical Bills	39%	29%	33%	27%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

(41-48%) of middle- and high-income earners. Additionally, nearly 1 in 3 (31%) of respondents with household incomes of $50,000 or less reported not filling a prescription, skipping doses of medicines or cutting pills in half due to cost, compared to roughly 1 in 4 respondents in other income brackets.

Lower-income individuals also most frequently reported financial consequences after receiving healthcare services—thirty-nine percent either went into medical debt, depleted their savings or sacrificed other basic needs (like food, heat or housing) due to medical bills.

Disability Status

People with disabilities interact with the healthcare system more often than those without disabilities and, as a result, tend to face more out-of-pocket costs.[4] Additionally, people who receive disability benefits face unique coverage challenges that impact their ability to afford needed care, such as the possibility of losing coverage if their household income or assets increase over a certain amount (for example, after getting married).[5]

Illinois respondents who have/live with a person with a disability more frequently reported a diverse array of affordability burdens compared to others (see Table 3). These individuals also more frequently reported worrying about healthcare affordability in general (90% vs. 76%) and losing health insurance specifically (44% vs. 27%).

Table 3

Percent Who Experienced Healthcare Affordability Burdens, by Disability Status

	Household Includes a Person with at Least One Disability	Household Does Not Include a Person with at Least One Disability
Any Healthcare Affordability Burden	79%	49%
Any Healthcare Affordability Worry	90%	76%
Rationed Medication Due to Cost	45%	19%
Delayed/Went Without Care Due to Cost	72%	40%
Incurred Medical Debt, Depleted Savings and/or Sacrificed Basic Needs due to Medical Bills	55%	24%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

Gender

The survey also surfaced differences in healthcare affordability burdens and worry by gender identity. Respondents identifying as women were more likely to report having experienced at least one affordability burden in the past year than those identifying as men (**61%** vs. **53%**) (see Table 4). While women more frequently reported delaying or going without care due to cost in general, men were slightly more likely to report rationing their medications by not filling a prescription, skipping doses or cutting pills in half.

While most respondents of both genders reported being somewhat or very concerned, a higher percentage of women reported worrying about affording some aspect of coverage or care than men (**83%** vs. **75%**).

Due to small sample sizes, this survey could not produce reliable estimates exclusively for transgender or genderqueer/nonbinary respondents. However, it is important to note that these groups experience unique healthcare affordability burdens—1.3% of survey respondents (14 adults) reported that they or a family member had trouble affording the cost of gender-affirming care, such as hormone therapy or reconstructive surgery.

Table 4
Percent Who Experienced Healthcare Affordability Burdens, by Gender Identity

	Men	Women
Any Healthcare Affordability Burden	53%	61%
Any Healthcare Affordability Worry	75%	83%
Rationed Medication Due to Cost	27%	25%
Delayed/Went Without Care Due to Cost	44%	54%
Incurred Medical Debt, Depleted Savings and/or Sacrificed Basic Needs due to Medical Bills	33%	32%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey
Note: Due to small sample sizes, we could not produce reliable statistics exclusively for individuals who identify as transgender or genderqueer/nonbinary. We regret that we were unable to supply additional information on healthcare affordability issues in these communities.

Distrust and Mistreatment in the Health System

Whether a patient trusts and/or feels respected by their healthcare provider can impact whether they seek needed care. In Illinois, nearly 1 in 3 (**29%**) of respondents reported that their provider never, rarely or only sometimes treats them with respect. When asked *why* they felt healthcare providers did not treat them with respect, nearly half of respondents cited their income or financial status (**47%**), followed by race (**32%**), ethnic background (**27%**) and physical, mental or cognitive disability (**22%**). In lesser numbers, respondents cited gender/gender identity (**14%**), sexual orientation (**14%**) and experience with violence or abuse (**10%**) as reasons for the disrespect.

Black/African American respondents, Hispanic/Latinx respondents and those with a person with a disability in their household more frequently reported distrust in and feeling disrespected by their healthcare providers than their white or non-disabled counterparts (see Table 5). They also more frequently went without medical care due to that distrust and/or disrespect. Forty-one percent of Black/African American respondents and **36%** of Hispanic/Latinx respondents reported taking this action, compared to **20%** of white respondents. Forty-one percent of respondents who have/are living with a person with a disability went without care due to distrust/disrespect, compared to **17%** of those without a household member with a disability.

Table 5

Percent who Distrusted/Felt Disrespected by a Healthcare Provider in the Last Year, by Race/Ethnicity and Disability Status

	Distrusted or Felt Disrespected by a Healthcare Provider	Went without Needed Care Due to Distrust of/ Disrespect by a Healthcare Provider
All Respondents	40%	24%
Race/Ethnicity		
Black/African American	61%	41%
Hispanic/Latninx	60%	36%
White	34%	20%
Disability Status		
Household Includes a Person with at Least One Disability	56%	41%
Household Does Not Include a Person with at Least One Disability	33%	17%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

Individual and Systemic Racism

Respondents perceived that both individual *and systemic* racism exist in the U.S. healthcare system. Sixty-one percent of respondents believe that people are treated unfairly based on their race or ethnic background, either sometimes or very often. When asked what they think causes healthcare systems to treat people unfairly based on their race or ethnic background:

- 1 in 5 (**21%**) cited policies and practices built into the healthcare system;
- 1 in 4 (**24%**) cited the actions and beliefs of individual healthcare providers; and
- nearly half (**44%**) believe it is an equal mixture of both.

Disatisfaction with the Health System and Support for Change

Given this information, it is not surprising that **65%** of respondents agree or strongly agree that the U.S. healthcare system needs to change. Understanding how the healthcare system disproportionately harms some groups of people over others is key to creating a fairer and higher value system for all.

Making healthcare affordable for all residents is an area ripe for policymaker intervention, with widespread support for government-led solutions across party lines. For more information on the types of strategies Illinois residents want their policymakers to pursue, see: *Illinois Residents Struggle to Afford High Healthcare Costs; Worry About Affording Future Care; Support a Range of Government Solutions Across Party Lines*, Healthcare Value Hub, Data Brief No. 117 (April 2022).

Notes

1. Fadeyi-Jones, Tomi et al., *High Prescription Drug Prices Perpetuate Systemic Racism. We Can Change It*, Patients for Affordable Drugs Now (December 2020).

2. Kaplan, Alan and O'Neill, Daniel, "Hospital Price Discrimination Is Deepening Racial Health Inequity," *New England Journal of Medicine—Catalyst* (December 2020).

3. A small share of respondents also reported barriers to care that were unique to their ethnic or cultural backgrounds. Two percent reported not getting needed medical care because they couldn't find a doctor of the same race, ethnicity or cultural background as them or they couldn't find a doctor who spoke their language.

4. Miles, Angel L., *Challenges and Opportunities in Quality Affordable Health Care Coverage for People with Disabilities*, Protect Our Care Illinois (February 2021).

5. A 2019 Commonwealth Fund report noted that people with disabilities risk losing their benefits if they make more than $1,000 per month. According to the Center for American Progress, in most states, people who receive Supplemental Security are automatically eligible for Medicaid. Therefore, if they lose their disability benefits they will also lose their Medicaid coverage. *Forbes* has also reported on marriage penalties for people with disabilities, including fears about losing health insurance.

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ABOUT ALTARUM'S HEALTHCARE VALUE HUB

With support from the Robert Wood Johnson Foundation, the Healthcare Value Hub provides free, timely information about the policies and practices that address high healthcare costs and poor quality, bringing better value to consumers. The Hub is part of Altarum, a nonprofit organization with the mission of creating a better, more sustainable future for all Americans by applying research-based and field-tested solutions that transform our systems of health and healthcare.

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Methodology

Altarum's Consumer Healthcare Experience State Survey (CHESS) is designed to elicit respondents' unbiased views on a wide range of health system issues, including confidence using the health system, financial burden and views on fixes that might be needed.

The survey used a web panel from Dynata with a demographically balanced sample of approximately 1,000 respondents who live in Illinois. The survey was conducted in English or Spanish and restricted to adults ages 18 and older. Respondents who finished the survey in less than half the median time were excluded from the final sample, leaving 1,012 cases for analysis. After those exclusions, the demographic composition of respondents was as follows, although not all demographic information has complete response rates:

Demographic Composition of Survey Respondents

Demographic Characteristic	Frequency	Percentage
Household Income		
Under $20K	145	14%
$20K - $30K	118	12%
$30K - $40K	98	10%
$40K - $50K	105	10%
$50K - $60K	104	10%
$60K - $75K	90	9%
$75K - $100K	144	14%
$100K - $150K	140	14%
$150K+	68	7%
Age		
18-24	173	17%
25-34	171	17%
35-44	135	13%
45-54	138	14%
55-64	192	19%
65+	193	19%
Health Status		
Excellent	155	15%
Very Good	317	31%
Good	366	36%
Fair	141	14%
Poor	33	3%
Disability		
Mobility: Serious difficulty walking or climbing stairs	171	17%
Cognition: Serious difficulty concentrating, remembering or making decisions	98	10%
Independent Living: Serious difficulty doing errands alone, such as visiting a doctor's office	65	6%
Hearing: Deafness or serious difficulty hearing	74	7%
Vision: Blindness or serious difficulty seeing, even when wearing glasses	51	5%
Self-Care: Difficulty dressing or bathing	40	4%
No disability or long-term health condition	703	69%

Demographic Characteristic	Frequency	Percentage
Gender		
Woman	586	50%
Man	406	49%
Transwoman	4	<1%
Transman	2	<1%
Genderqueer/Nonbinary	8	<1%
Insurance Status		
Health insurance through employer or family member's employer	364	36%
Health insurance I buy on my own	81	8%
Medicare	312	31%
Medicaid	181	18%
TRICARE/Military Health System	8	1%
Department of Veterans Affairs (VA) Health Care	8	1%
No coverage of any type	35	3%
I don't know	23	2%
Race/Ethnicity		
American Indian or Native Alaskan	38	4%
Asian	34	3%
Black or African American	141	14%
Native Hawaiian or Other Pacific Islander	3	<1%
White	799	79%
Prefer Not to Answer	14	1%
Two or More Races	32	3%
Hispanic or Latinx – Yes	131	13%
Hispanic or Latinx - No	881	87%
Party Affiliation		
Republican	268	26%
Democrat	420	42%
Neither	324	32%

Source: 2021 Poll of Illinois Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

Notes: Percentages in the body of the brief are based on weighted values, while the data presented in the demographic table is unweighted, except for race/ethnicity. We do not conduct statistical calculations to determine the significance of differences in findings. Comparisons are for conversational purposes only and are determined by advocate partners in each state based on organizational/advocacy priorities. We do not report any estimates under N=100 and a co-efficient of variance more than .30.