Patient perspectives on health insurance design: Experiences of beneficiaries with chronic diseases

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Introduction

- Over 90% of Americans now have health insurance,[1] yet many reports suggest challenges such as high patient out-of-pocket (OOP) costs, burdensome utilization management requirements, and denials of prescribed medications.
- In the United States, nearly 45% of non-senior adults live in families facing healthcare-related financial difficulties,[2] and about 23% of adults struggle with medical debt.[3]
- Approximately 60% of Americans have a chronic illness.[4]
- Cost-sharing mechanisms in insurance often leave patients with chronic diseases facing substantial, unaffordable expenses—a phenomenon referred to as "insured but not covered".[5,6]
- These issues highlight the need to reform current benefit designs to meet the specific needs of individuals with chronic illnesses.[5]

Research objective

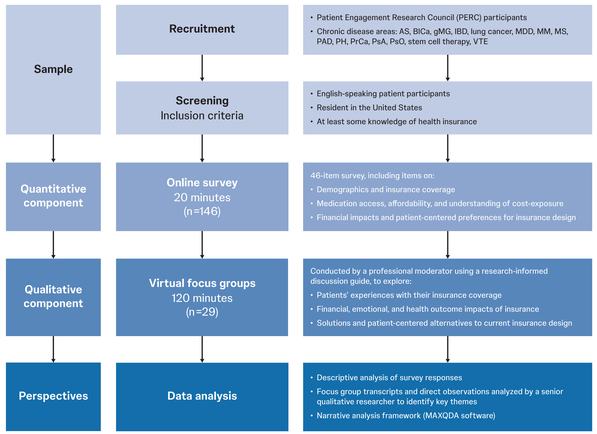
- To gather insights directly from chronic disease beneficiaries regarding their lived experiences and perspectives on health insurance coverage to inform discussions on optimizing benefit design.

Methodology

Study design

- A mixed-methods study was conducted with US residents living with chronic diseases and continuous health insurance coverage, using an online survey and virtual focus group discussions (**Figure 1**).
- Participants were recruited from the Patient Engagement Research Council (PERC), a program led by Johnson & Johnson that engages a diverse group of patients with chronic health conditions to provide insights through structured research activities.[7–9] Participant demographics are shown in **Table 1**.
- Participation was voluntary, written informed consent was obtained, and participants were compensated at fair market value for their time.
- The study did not include discussions about specific pharmaceutical products, health plans, or insurance carriers, and researchers were unaware of participants' potential use of specific products or their affiliation with particular health plans.
- This study was deemed exempt from institutional review board approval pursuant to the terms of the U.S. Department of Health and Human Service's Policy for Protection of Human Research Subjects at 45 C.F.R. §46.104(d).

FIGURE 1: Study design



AS, ankylosing spondylitis; **BICa**, bladder cancer; **gMG**, generalized myasthenia gravis; **IBD**, inflammatory bowel disease; **MDD**, major depressive disorder; **MM**, multiple myeloma; **MS**, multiple sclerosis; **PAD**, peripheral artery disease; **PH**, pulmonary hypertension; **PrCa**, prostate cancer; **PsA**, psoriatic arthritis; **PsO**, psoriasis; **VTE**, venous thromboembolism.

Survey research

- A 46-item online survey was distributed to 204 PERC members, of whom 146 patients across 15 chronic diseases completed the survey between August 30 and September 6, 2023.
- The survey captured demographic and insurance coverage information, as well as participants' perspectives on medication access, affordability, cost-exposure, financial impact, and preferences for potential changes to insurance design (the full questionnaire is in the digital supplement).
- Survey data were analyzed using descriptive statistical methods to summarize key themes and trends.

Focus group engagements

- Six virtual focus groups, each lasting 120 minutes, were conducted between November 29 and December 7, 2023, to collect in-depth qualitative insights based on feedback gathered from the survey.
- A total of 29 survey participants were invited to join the focus groups. Participant selection focused on ensuring a breadth of viewpoints based on age, race/ethnicity, gender, disease area, and insurance type, matching the composition of survey participants (**Table 1**).
- Discussions centered on lived experiences and perspectives related to medication access, affordability, cost-sharing, and potential benefit design changes.
- Focus group transcripts and observations underwent thematic analysis using MAXQDA software; a narrative analysis framework was applied to code data based on predefined topics and participants' lived experiences.

TABLE 1: Demographics and insurance types of survey respondents and focus group participants

Parameter	Survey respondents (n=146)	Focus group participants (n=29)
Age, years, median (range)	57.0 (23.0–81.0)	56.5 (31.0–80.0)
Age category, years, n (%)		
18–39	20 (14)	4 (14)
40–59	62 (42)	11 (38)
60–79	61 (42)	13 (45)
≥80	3 (2)	1 (3)
Gender, n (%)		
Female	91 (62)	17 (59)
Male	52 (36)	11 (38)
Non-binary	3 (2)	1 (3)
Race/ethnicity,[a] n (%)		
White	81 (55)	18 (62)
Black/African American	38 (26)	8 (28)
Hispanic/Latino	15 (10)	1 (3)
Asian American/Pacific Islander	7 (5)	2 (7)
Other	5 (3)	0
Highest level of education, n (%)		
Post-graduate	45 (31)	7 (24)
Bachelor's degree	49 (33)	10 (34)
Associate degree	5 (3)	1 (3)
Trade school	9 (6)	2 (7)
Some college	28 (19)	6 (21)
High school	8 (5)	1 (3)
Other	3 (2)	2 (7)
Annual household income,[b] n (%)		
<$40,000	35 (24)	7 (24)
$40,000 to $79,999	27 (18)	7 (24)
$80,000 to $119,000	42 (29)	6 (21)
≥$120,000	34 (23)	8 (28)
Not sure/prefer not to say	8 (5)	1 (3)
PERC chronic disease category, n (%)		
Cardiovascular[c]	24 (16)	5 (17)
Immunology[d]	49 (34)	13 (45)
Neurology[e]	15 (10)	1 (3)
Oncology[f]	45 (31)	6 (21)
Pulmonary[g]	13 (9)	4 (14)
Health insurance plan, n (%)		
Employer-based only	56 (38)	12 (41)
Medicare only	39 (27)	9 (31)
≥1 insurance type	36 (25)	8 (28)
Medicaid only	11 (8)	0
TRICARE or Veterans Affairs only	2 (1)	0
Marketplace/Exchange only	2 (1)	0

[a]Individuals could identify as more than one race/ethnicity. [b]In US dollars. [c]Cardiovascular: peripheral arterial disease, venous thromboembolism. [d]Immunology: ankylosing spondylitis, generalized myasthenia gravis, inflammatory bowel disease, psoriasis, psoriatic arthritis, stem cell therapy. [e]Neurology: major depressive disorder, multiple sclerosis. [f]Oncology: bladder cancer, lung cancer, multiple myeloma, prostate cancer. [g]Pulmonary: pulmonary hypertension.

PERC, Patient Engagement Research Council.

Results

General satisfaction

- 76% of survey respondents considered their health insurance valuable, and 73% were satisfied with the clarity of information about coverage and prescription medication costs. 44% felt their insurance provider showed concern for their wellbeing and long-term health.
- In focus group discussions, participants expressed fluctuation in satisfaction over time due to life events, such as retirement or employment changes, which significantly impacted financial stability and insurance coverage.
- Approximately one-quarter of focus group participants reported that their insurance provided little value, largely due to unaffordable medication costs and coverage gaps, including mental health services.

Patient affordability

- 23% of survey respondents said they struggled to afford prescription medications despite insurance coverage, with cost-sharing (35%) and high deductibles (24%) noted as key barriers.
- High OOP costs remained a significant concern even among those with top-tier insurance plans, leading to examples of patients being forced to rely on spousal income, incur medical debt, or forgo essential care.
- Affordability challenges disproportionately affected respondents on lower incomes, with 50% of those earning less than US$40,000 annually unable to afford their OOP costs.

Financial unpredictability

- While 86% of survey respondents recalled discussing clinical benefits of new medications with their provider, fewer than 23% remembered discussing costs.
- Only 16% of respondents felt confident they understood their prescription medication costs when selecting their health insurance plan.
- Despite 58% of respondents researching costs before receiving their medications, 23% could never find the information, and 21% found the information they gathered to be inconsistent.
- Over half (58%) of survey respondents found that actual medication costs differed from expectations.
- Focus group participants highlighted challenges with inconsistent OOP cost burdens and inaccurate copay estimates, which particularly impact those with rare diseases or needing newly approved medications.

Financial burden

- 11% of survey respondents reported spending more than US$2,000 (not including premiums) over the previous 12 months on drug OOP costs despite having insurance; 3% had spent more than US$5,000.
- Due to high OOP costs, 18% of respondents reported having to reduce spending on basic needs, 13% took on debt, and 15% abandoned medications.
- The financial strain disproportionately impacted non-White respondents, who comprised 63% of those reducing basic needs, 79% of those incurring debt, and 68% of those abandoning medications.
- Focus group discussions further emphasized the detrimental impact of cost-exposure (**Table 2**).

TABLE 2: Focus group participants' experiences of the financial burden of OOP costs

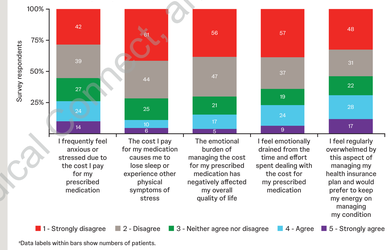
Patient strategies to afford medication	Example patient perspectives
Reduced household spending on food and bills	"I know how to be creative. I got to be creative with my bills [such as] food bills, because a big chunk of my check is going towards my medical, and I don't want to be surprised by my medical bill when I'm being charged [so much]." — Psoriasis, male "It could affect missing a bill, leave us short on grocery money, [force us to] do what we need to do until... we have the money." — Inflammatory bowel disease, female
Going without gas/electricity	"There were a couple of times my utilities were disconnected because I had to have this medication, and it was a hardship." — Stem cell therapy, male
Taking on debt	"I'm trying to figure out where I'm going to get money to get my kids Christmas presents, I don't know how much room I have on my credit cards ... it's frustrating." — Generalized myasthenia gravis, male
Declaring bankruptcy	"I have filed bankruptcy twice in my life. I'm only 42, I mean, when you're 18, and you're $10,000 in debt, what do you do? ... We spent over $10,000 [each year] on medication. And we did that three years in a row, and my husband only made $38,000 at that time. So, you can only imagine. We had no money." — Inflammatory bowel disease, female
Skipping doses or abandoning medication	"The insurance stopped covering it altogether, so that went way up... I had to stop that for quite some time until I could work that into the budget." — Venous thromboembolism, female "I'll try to stretch [my meds] because I can only afford a month. I'll just take half and try to get by until I can get the next month's dosage." — Inflammatory bowel disease, female
Borrowing money	"I've encountered medications that were very difficult to afford and I had to borrow money from family to pay for them." — Lung cancer, male "I asked just somebody that I'm nearly a complete stranger with [for] $20 because I had to get to the pharmacy and get my medicine." — Multiple sclerosis, female
Patient assistance programs	"I was able to get a charity to help out with my medical costs now. So I have to pay it up front and then I can submit it for reimbursement and that helps so much." — Generalized myasthenia gravis, male

OOP, out-of-pocket.

Emotional and physical impact

- 26% of survey respondents (38 patients) admitted frequent feelings of anxiety and stress about OOP medication costs, with some reporting loss of sleep, reduced overall quality of life, and feeling emotionally drained as a result (**Figure 2**).

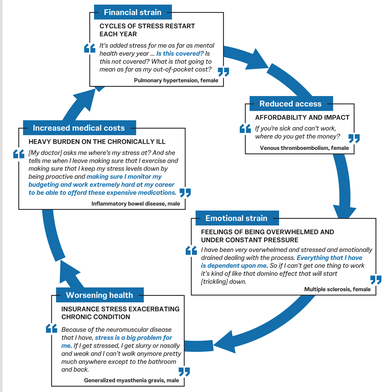
FIGURE 2: Emotional impact of managing the cost of prescriptions over the previous 12 months (survey respondents; n=146)[a]



[a]Data labels within bars show numbers of patients.

- Focus group participants provided additional in-depth descriptions of challenges affecting their stress and anxiety levels that contributed to an overall sense of insurance fatigue, including uncertainty of coverage, failure to cover prescription medication costs, and difficulty troubleshooting issues (**Figure 3**).
- Participants suggested that the stress caused by insurance issues was linked to increased disease activity or flares. Every focus group had participants mention skipping doses, stretching out medication, or completely abandoning medication due to lack of access, resulting in worsening health outcomes.

FIGURE 3: Stress/anxiety arising from inadequate insurance design throughout the patient journey



Perspectives on changes to benefit design

Trade-offs acceptable to reduce cost burden

- Most respondents supported revisions to insurance design, prioritizing reductions in medication cost-sharing even if it meant slightly higher premiums for all: 79% preferred reducing or eliminating cost-sharing, and 82% were willing to pay more for insurance to lower their direct OOP costs.
- There was strong support for insurance benefits that improve affordable access to new and innovative medications, which was deemed important by 96% of respondents.

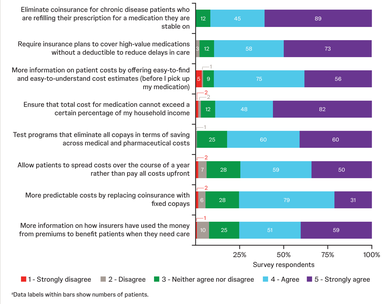
Type of cost-exposure matters

- Respondents expressed a strong preference for predictable medication costs, with 51% supporting fixed copays, 52% favoring no OOP costs for medication refills for patients with stable disease, and 97% opposing (variable) coinsurance requirements at every refill.
- 78% of respondents believed eliminating OOP costs would not lead to overuse of medications, with 89% reporting that their treatment use would continue to be driven by the clinical benefits of prescribed medications.

Patients embrace multiple policy solutions

- Survey respondents broadly supported multiple policy solutions for redesigning health insurance (**Figure 4**).
- Focus group discussions emphasized the importance of educational efforts to clearly explain design changes and their direct benefits to patients (see digital supplement for detailed contextualization).

FIGURE 4: Patient support for proposed changes to health insurance (survey respondents; n=146)[a]



[a]Data labels within bars show numbers of patients.

Conclusions

Value of insurance: Study participants valued having health insurance but also reported significant barriers due to high deductibles, cost-sharing, and lack of transparency in costs. The compounding of these issues left some patients functionally uninsured—forcing them to incur debt or forgo essential care—and participants perceived that insurance problems had exacerbated their health conditions.

OOP cost impacts: Financial concerns about OOP costs had a substantial impact on participants' mental health, quality of life, and treatment adherence. Nearly one-third expressed feeling overwhelmed. Coping mechanisms like skipping, stretching, or abandoning medications in response to medication unaffordability at the pharmacy counter featured in every group discussion. Participants on lower incomes faced particular difficulties with affordability.

Reform: Participants were pragmatic about insurance reform, favoring greater predictability, fixed copays, and transparency. Endorsed solutions included eliminating (variable) coinsurance for prescription refills, capping medication costs relative to household income, and spreading costs over time.

Accepting trade-offs: Participants also believed premium increases can be acceptable if they effectively allow for reduced OOP cost burdens and improved access to medications.

Future insurance design: These findings offer valuable qualitative insights to inform actuarial modeling. Understanding patients' preferences will be critical in designing value-based insurance that balances societal costs with addressing the needs of chronic disease patients.

Key takeaways for AMCP decision-makers

- There is a persistent lack of evidence from real-world experiences of patients with chronic diseases to inform insurance design evolution.
- Current benefit designs can fall short in adequately reducing financial burdens for patients with chronic conditions, causing emotional distress and risks of disease worsening.
- This study highlights the importance of designing health insurance to align with the values and needs of patients with chronic diseases, which affect 60% of Americans.

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