EACHPIC COALITION

UNDERSTANDING PATIENT PERSPECTIVES ON PRESCRIPTION DRUG AFFORDABILITY

PATIENT EXPERIENCE SURVEY 2.0

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ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

Unite allied organizations to share resources and collectively advocate for patient-first policies that protect access to medications

PATIENT INCLUSION COUNCIL

Patients and caregivers shaping healthcare policy by sharing their prescription drug affordability experiences and ensuring those needs are incorporated into drug affordability solutions

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PRESENTATION OVERVIEW

PATIENT-FACING DATA COLLECTION HISTORY & STUDY RATIONALE

RESULTS OF THE PATIENT EXPERIENCE SURVEY 2.0

APPLICABILITY TO PRESCRIPTION DRUG AFFORDABILITY BOARDS

PATIENT-FACING DATA COLLECTION HISTORY & STUDY RATIONALE

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Study Background

SURVEY PURPOSE

DETERMINE THE TRUE DRIVERS OF PATIENT AFFORDABILITY AND ACCESS CHALLENGES NOT CAPTURED IN YES/NO QUESTIONS

IDENTIFY POLICIES TO ADDRESS THE ROOT CAUSES OF PATIENT-REPORTED ISSUES (ADDRESS “THE WHY”)

BASED ON LESSONS LEARNED, ESTABLISH A ROBUST MODEL TO HELP WITH EFFECTIVE PATIENT-FACING DATA COLLECTION

*This 18-month, two-phase study demonstrates that **properly worded patient-facing questions and open-ended comments** better capture patients' perspectives on the costs of their medications.*

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Study Background

STUDY DESIGN

ORIGINAL PILOT: PATIENT RESEARCH PARTNERS, PATIENT ORGS ESTABLISHED ENDPOINTS & QUESTIONS (51); LARGELY PATIENT ORG RECRUITED

DATA SCIENTIST - MISTY KNIGHT-FINLEY, PHD, INFORM ANALYTICS - FINALIZED QUESTIONS, LED ANALYSIS

PILOT (80-100 PEOPLE) ESTABLISHED PROOF OF CONCEPT TOOL & "THE WHY" - USED RESULTS TO EDIT & STREAMLINE FULL STUDY 2.0 QUESTIONS (21)

View last round of quesitons

FULL STUDY 2.0 (538 PEOPLE) EXPANDED DEMOGRAPHICS & SAMPLE SIZE, TARGETED STATES & CONDITIONS; LARGELY PAID RESPONDENTS (SURVEYMONEY)

Design addressed the serious disconnect patients identified between their real-world experience and the simplified surveys used in affordability reviews.

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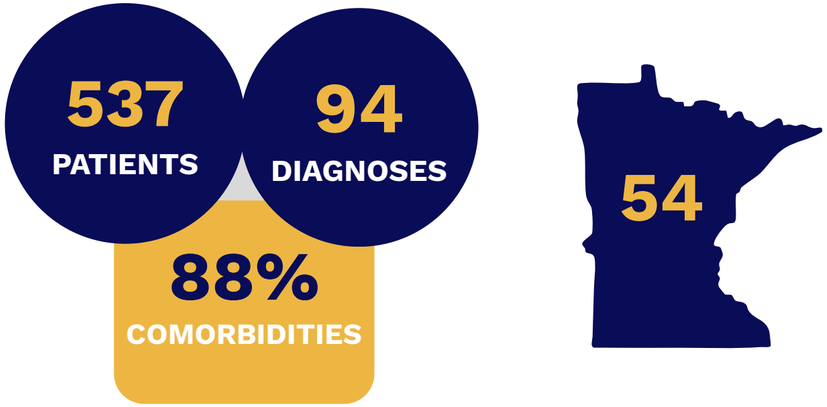
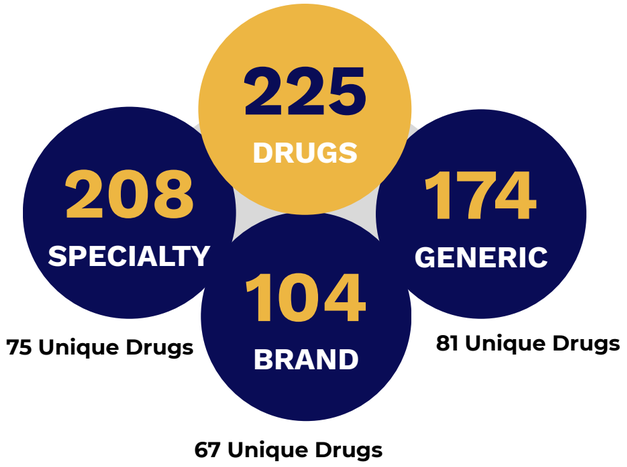
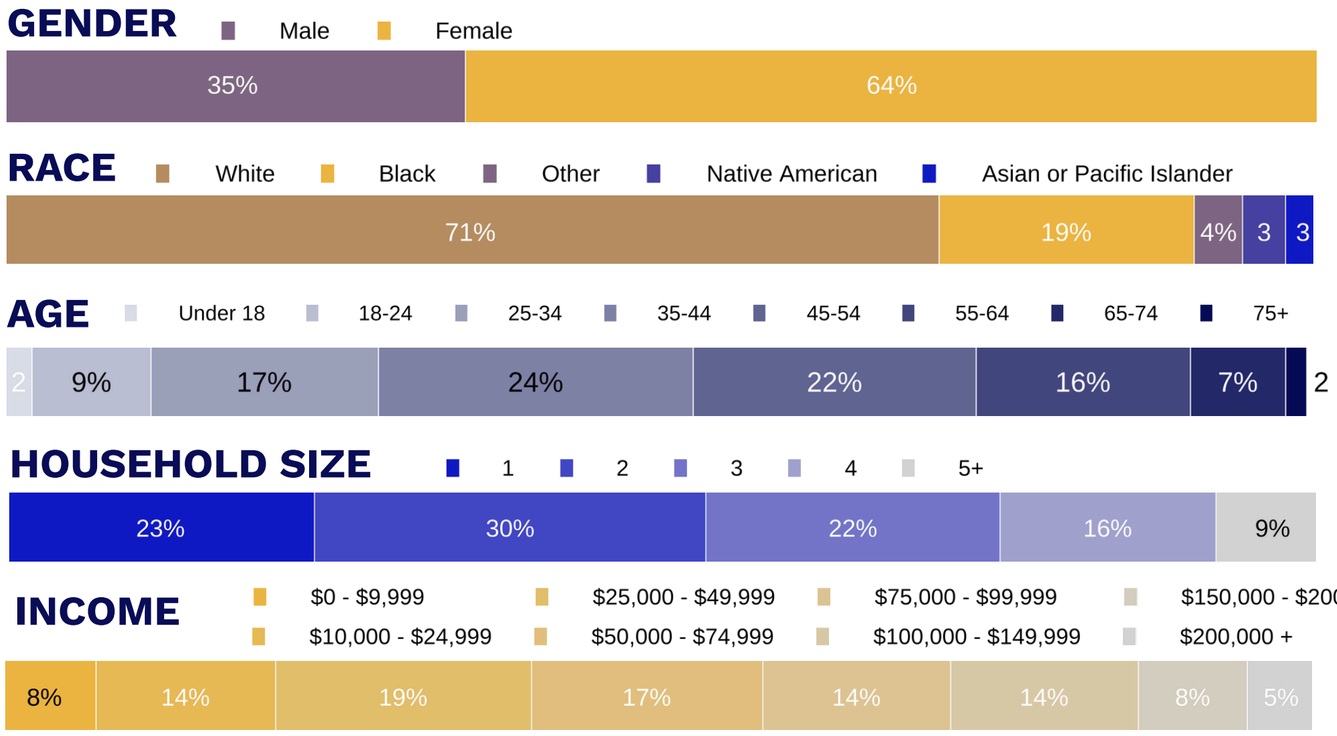
Survey Results

DEMOGRAPHICS

Survey responses came from paid (SurveyMonkey) and unpaid respondents recruited through patient advocacy organizations, patients, and word-of-mouth.







71% of persons of color and 55% of non-Hispanic white respondents reported on brand and generic drugs.

RESULTS OF THE PATIENT EXPERIENCE SURVEY 2.0

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Survey Results

KEY FINDINGS

CONTEXT IS CRITICAL TO UNDERSTANDING PATIENT-REPORTED AFFORDABILITY

INSURANCE IS A KEY DETERMINANT OF PATIENT-REPORTED AFFORDABILITY AND ACCESS TO TREATMENTS

PATIENTS' SHARE OF COSTS ARE OFTEN UNSTABLE OVER TIME

MEDICATIONS ARE NOT INTERCHANGEABLE

By focusing on the price of a single prescription drug, decision-makers miss critical information about patients' broader challenges.

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Survey Results

CONTEXT IS KEY

WHAT IS LEARNED WHEN ASKING WHY (OPEN-ENDED RESPONSES): AS CONFIRMED FROM OUR PILOT SURVEY, AND CONSISTENT WITH THE NEW PATIENT-REPORTED DEFINITION OF PRESCRIPTION DRUG AFFORDABILITY, RANKING A DRUG AT **ANY PRICE POINT** AS AFFORDABLE OR UNAFFORDABLE DEPENDED ON:

INSURANCE COVERAGE

PERSONAL INCOME

LIFE CIRCUMSTANCES

CUMULATIVE COSTS

OPINIONS ON DRUG COSTS

*200 patients defined affordability as "the ability to consistently obtain medications within **their essential monthly household budget**, considering income, total healthcare costs, and life circumstances."*

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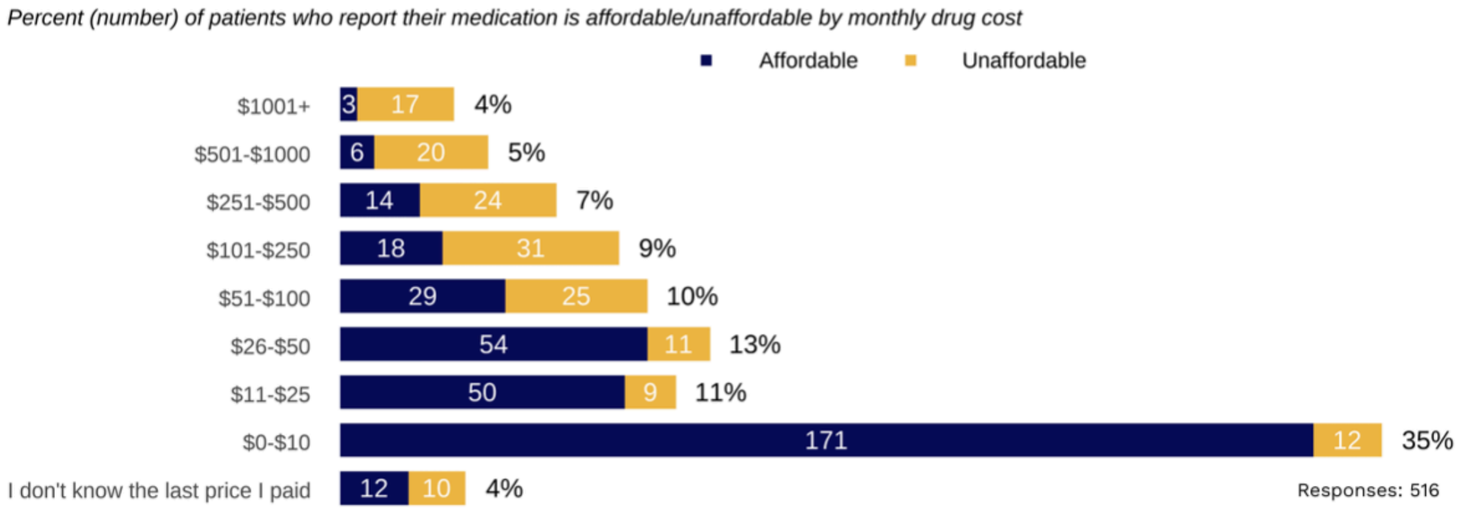
Survey Results

CONTEXT IS KEY

"Respondents were asked, "Thinking of **the last time** you took [drug], what was the monthly out-of-pocket cost you paid?" Choices were $0-10, $11-25, $26-50, $51-100, $101-250, $251-500, $501-1000, $1001+.

They were then asked, "Do you consider this **affordable or unaffordable? Explain why." Here is the breakdown of the last out-of-pocket cost.**

69% AFFORDABLE | **31% UNAFFORDABLE**



*But **why**?*

By focusing on the retail or net cost of a single prescription drug, and not asking patients 'why' they can or cannot afford the medication, decision-makers miss critical information that can be used to help patients afford their medications.

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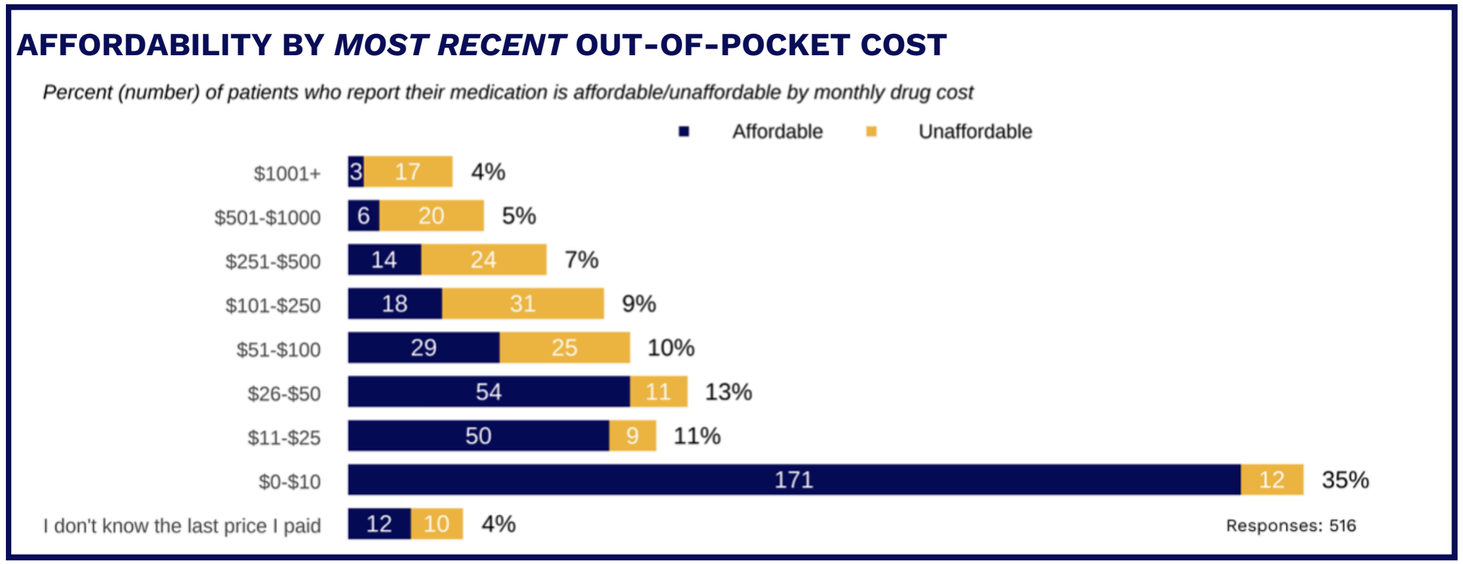
Survey Results

CONTEXT IS KEY - DEEPER DIVE INTO THE WHY

AFFORDABILITY DID NOT SOLELY ALIGN WITH THE RETAIL PRICE OF THE DRUG



TOP DRIVER:
INSURANCE COVERAGE

- **Last OOP cost vs lifetime cost:** Insurance-driven instability derived from coverage decisions, cost-sharing variability, and restrictions on using financial assistance
- **Employer based plans** emerged as creating hardships due to high deductible and OOP max plans & limitations to financial assistance

Income, cumulative costs, life situations: 20% in the pilot and 7% in this 2.0 survey of reported $0-$10 is unaffordable.

Research concluded that no one drug created affordability hardships for any group of people - not even when reported on over 30 times.

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Survey Results

INSURANCE BARRIERS

TO HELP PATIENTS AFFORD & ACCESS TREATMENTS, "COST" BARRIERS REQUIRE CONTEXT

95% OF PATIENTS WHO **STOPPED TAKING THEIR MEDICATION** FOR COST REASONS CITED INSURANCE-RELATED CHALLENGES

- 77%: Insurer removed from formulary, accumulators, step therapy, non-medical switching, and dosage caps
- 100% reported insurance-related in the pilot

72% OF PATIENTS WHO **NEVER STARTED** A MEDICATION CITED INSURANCE-RELATED CHALLENGES

- 90% of those who provided "the why" cited denial of insurance coverage & high copays
- Recurring theme - potential lack of knowledge financial assistance is available

75% FROM PILOT: THOSE WHO **SKIPPED OR STRETCHED A DOSE** DID SO DUE TO INSURANCE DELAYS, NOT THE COST OF THE MEDICATION

- Only 14% cited OOP drug cost alone as the reason for missed doses, and even these patients often had low costs. Many added "cumulative costs", not this drug alone, matters.

TOP "WHY": *"Insurance wouldn't cover it."*

INSURANCE QUANTITY CAPS:
"I try to ration the sessions for my worst migraines but often go months between refills because of the cost."

FINANCIAL ASSISTANCE:
"[I was] "approved" [for] Ilaris on 1/30/25, but I had to fight repeatedly to get the specialty pharmacy to follow through. I didn't receive a dose until MAY."

Current surveys that do not ask "why" result in incomplete and potentially inaccurate data.

Read detailed report on the 52 people who gave a reason for stopping their medication

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Survey Results

INSURANCE BARRIERS CONT'D: SHIFTING COSTS = SHIFTING AFFORDABILITYAND ACCESS

In an attempt to discover an affordability threshold, researchers asked for respondents to report **all OOP costs ever paid** for the drug, then report if that was affordable or unaffordable and why.

"OUT-OF-POCKET COST SHIFTING"	41% of **all** those surveyed reported paying different out-of-pocket costs for the same medication at different times over their lifetime use.
"AFFORDABILITY SHIFTING"	51% reporting OOP cost shifting also reported **the same drug both affordable and unaffordable** at different times.
"ACCESS SHIFTING"	When OOP costs become unaffordable, many patients lost access to that treatment.

"I previously had Anthem and got this medication for a copay of $15 a month. I now have United Healthcare and they will not cover it. Out-of-pocket cash price is over $700 a month. I can't use a savings card because that medication must be on their formulary. I am now going without this medication and am now having daily migraines."

- Out-of-pocket costs for the same drug, same person from $0-$1001

90% of people describing affordability shifting cited insurance plan barriers including high deductibles, out-of-pocket maximums, and coverage denials.

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Survey Results

FINANCIAL ASSISTANCE

AFFORDABLE OFTEN MEANS “AFFORDABLE WITH ASSISTANCE”

71% STATED FINANCIAL ASSISTANCE WAS THE REASON WHY THEIR MEDICATION WAS AFFORDABLE (PILOT AND 2.0)

72% REPORTED APPLYING FOR **MANUFACTURER’S COPAY ASSISTANCE** WAS “EASY”. HAVING THE INSURANCE COMPANY APPLY IT WAS NOT AS EASY. (PILOT)

IDENTIFIED ISSUE: IN BOTH THE PILOT AND 2.0, RESPONDENTS STRUGGLED TO DIFFERENTIATE TYPES OF FINANCIAL ASSISTANCE, REPORTED DELAYED OR DENIED ASSISTANCE, AND MANY - PARTICULARLY ON EMPLOYER OR INDIVIDUAL INSURANCE - MADE NO MENTION OF APPLYING FOR FINANCIAL ASSISTANCE WHEN HAVING HIGH OUT OF POCKET COSTS.

Examples of answers to open-ended question, “Why is your drug affordable or unafforable?”

"I started new insurance and applied for the manufacturer assistance, which took about 2 minutes. I ordered from the specialty pharmacy and no med arrived. Called back, they ‘forgot’ to apply my copay card. Ordered again, then got no med and a bill for $5,000. Finally in April - after skipping doses, I got it for $0."

“While I did not have any issues applying for assistance, my insurance company does require I call and get the approval monthly for my copay assistance which takes anywhere from 20 minutes to 3 hours every month.”

Awareness of available financial assistance and policies that do not hinder access to them are vital to improving affordability.

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Survey Results

PRESCRIPTION DRUG VALUE

MEDICATIONS ARE NOT INTERCHANGEABLE

>80% OF PATIENTS WHO TRIED MULTIPLE TREATMENTS DESCRIBED THEIR MEDICATION AS VALUABLE, WITH MOST EMPHASIZING ITS UNIQUE VALUE TO THEM

82% OF 60 PATIENTS WITH RHEUMATOID ARTHRITIS TRIED MORE THAN ONE SPECIALTY MEDICATION BEFORE FINDING ONE THAT WORKED

49% OF THOSE PATIENTS HAD COMORBIDITIES THAT COULD IMPACT THEIR TREATMENT DECISIONS

Examples of answers to open-ended question, "How valuable would you say this drug is for you/others?"

Several people reporting on the same biologic drugs reported varied value:

- *"I couldn't live without it."*
- *"Great for others, but not for me."*

Cycling through to find the one that works: *"Humira is a medication I am using after failing five other medications."*

Comorbidities:
"My biologic is extremely valuable. It is one of the best options to treat Scleroderma and Interstitual Lung Disease."

Protecting access to the treatment that works for each individual patient is as important as managing costs.

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Survey Results

PRESCRIPTION DRUG VALUE CONT'D

NON-MEDICAL SWITCHING CAUSED PATIENT HARM AND OVERRIDES VALUE

NON-MEDICAL SWITCHING OCCURRED NOT ONLY FOR THOSE WITH EXISTING INSURANCE, BUT ALSO WHEN CHANGING INSURANCE (NO FORMULARY COVERAGE)

SOME "UNAFFORDABILITY" RANKINGS WERE BASED ON WANTING TO STAY ON THE MEDICATION AND CHOOSING TO PAY FULL PRICE

DISEASE RECURRENCE

ADVERSE EVENTS

WORSENED HEALTH OUTCOMES

"When I dealt with a forced non-medical switch my life flipped upside down. I went from being in remission for nine years to being debilitated for almost two months, this was extremely upsetting and really messed with my life as a mom of three young kids."

"My insurance (Medicaid) would not cover semaglutide, even with preauthorizations. They forced me to go through step therapy, and when those drugs were not working, I paid for the medication out of pocket to manage my disease."

Utilization management practices that prioritized therapeutic alternatives interfered with patient-valued treatments and resulted in non-medical switching.

APPLICABILITY TO PRESCRIPTION DRUG AFFORDABILITY BOARDS

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PDAB
Applicability

KEY TAKEAWAYS

PATIENT-CENTERED AFFORDABILITY ASSESSMENTS ARE CRITICAL TO UNDERSTAND THE ROOT CAUSE OF PATIENT CHALLENGES

EFFECTIVE REFORMS MUST DIRECTLY BENEFIT PATIENTS AND ADDRESS PATIENT-REPORTED HARDSHIPS

PROTECTING ACCESS TO NECESSARY AND EFFECTIVE TREATMENTS MUST BE WEIGHED AS HEAVILY AS REDUCING COSTS

ACCURATE DATA = EFFECTIVE SOLUTIONS

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PDAB
Applicability

RESOLVE PATIENT PROBLEMS

DON’T ASSUME THAT PRICE TELLS THE WHOLE STORY, START WITH THE WHY

PRIORITIZE REFORMS THAT DIRECTLY LOWER OUT-OF-POCKET COSTS FOR PATIENTS

PROTECT PATIENTS FROM UNINTENDED CONSEQUENCES OF NEW POLICIES BY IMPLEMENTING PROTECTIONS BEFORE IMPLEMENTATION (MONITORING FOR HARM IS NOT ENOUGH)

The work of policymakers must be centered on the real-world challenges patients face in affording and accessing their prescribed medications.

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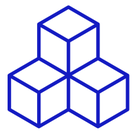
PURSUE PATIENT-FIRST POLICIES

MAKE PATIENT COSTS MANAGEABLE

- DIRECTLY ADDRESS PATIENT COSTS
- IMPLEMENT COST SMOOTHING OR PAYMENT PLANS

PROVIDE SUPPORT TO AVOID CATASTROPHIC COSTS

- EXPAND ACCESS TO AND EDUCATION ABOUT FINANCIAL ASSISTANCE PROGRAMS
- STREAMLINE AND PROTECT COPAY SUPPORT



ADDRESS STRUCTURAL DESIGNS THAT CAUSE HARDSHIP

- PROTECT PATIENTS FROM HARMFUL UTILIZATION MANAGEMENT
- ALIGN INCENTIVES WITHIN THE HEALTHCARE MARKETPLACE

To truly improve affordability, policymakers must move beyond narrow definitions of cost and center reforms on the lived experiences and immediate needs of patients.

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PDAB Applicability

ENHANCE PATIENT ENGAGEMENT BY COLLABORATING WITH PATIENT-FACING DATA COLLECTION EXPERTS

COMING SOON: Patient Inclusion Council (PIC) Led Patient-Facing Data Collection Toolkit

- IMPROVE SURVEY QUESTION DESIGN BY UTILIZING TESTED AND PROVEN MODEL
- OPTIMIZE TOWNHALLS, ROUNDTABLES, AND OTHER PATIENT-FACING DATA COLLECTION EFFORTS WITH GUIDANCE TO CAPTURE MEANINGFUL ENDPOINTS DURING OPEN CONVERSATION ENVIRONMENTS
- ENLIST COMPLIMENTARY HELP FROM PATIENT RESEARCH PARTNERS (PRPS) TO REVIEW PATIENT-FACING DESIGNED QUESTIONS NOT IN OUR TOOLKIT

TOOLKIT WILL ALSO INCLUDE LESSONS LEARNED FROM OUR SURVEY QUESTIONS (INCLUDING NECESSARY REVISIONS) AND ADDITIONAL PATIENT ENGAGEMENT BEST PRACTICE RECOMMENDATIONS.

Meaningful input from patients and caregivers is critical to ensuring that policy remedies appropriately address patient needs.

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THANK YOU

Affordability efforts must start and end with patients, and the primary goal must be to help them afford the medications they need.

We invite policymakers, advocates, and partners to use this data, engage with our coalition, and work collaboratively toward solutions that improve access, reduce harm, and reflect the realities patients face.

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