Transparency in Healthcare:

Does It Actually Help Patients?

A Policy Report from the Arthritis Healthcare Forum 2026

National Press Club • Washington, D.C. • April 28, 2026

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About This Report

This policy report presents findings from a national patient advocate survey conducted by the Arthritis Foundation in March 2026, alongside insights from expert panel discussion and recommendations from the Arthritis Healthcare Forum held on April 28, 2026. It is intended to inform state and federal policymakers, state insurance commissioners, healthcare system leaders and patient advocacy partners.

The survey reflects the experiences of 43 active patient advocate "Platinum Ambassadors" and examines transparency across key areas of healthcare, including costs, coverage, treatment decisions, clinical communication and data use. Findings were analyzed by staff of the Arthritis Foundation's Advocacy & Access Department and contextualized within current federal and state policy developments to identify gaps between policy intent and patient experience.

Forum Participants:

Patient Expert Panel (moderated by Hayley Dempsey, Federal Affairs Manager, Arthritis Foundation): Ela C. (IL), Christine C. (PA), Jennifer R. (FL), Candace R. (UT)

Policy/Industry Expert Panel (moderated by Alisa V. Casavant, Senior Director of Policy, Arthritis Foundation): Melissa Bartlett (ERIC), Paige Colston (American College of Rheumatology), Robert Tennant (WEDI), J.P. Wieske (Monument Advocacy)

Welcome & Opening Remarks: Michael Privette (Chief Development Officer), Cari Crady (National VP, Foundations & Corporate Partnerships), Anna Hyde (VP, Advocacy & Access)

EXECUTIVE SUMMARY

The State of Transparency in Arthritis Care

Over the past several years, policymakers and regulators have advanced a range of initiatives intended to improve transparency in healthcare. While these efforts have increased the availability of information, patients living with arthritis continue to report significant challenges in accessing, understanding and using that information to make decisions about their care.

Findings from the Arthritis Foundation's March 2026 patient advocate survey highlight a persistent gap between policy intent and patient experience. Transparency is widely valued but inconsistently delivered in ways that are timely, easily understood and actionable.

Patients report performing substantial administrative work to navigate the healthcare system, particularly when seeking clarity on health insurance coverage, prior authorization requirements and out-of-pocket costs. Despite existing transparency policies, cost uncertainty remains a leading barrier to timely care. At the same time, confidence in how health data is used is low, and new technologies like artificial intelligence are being adopted by patients as workarounds for gaps in the system.

This report presents key survey findings, examines how those align with current policy frameworks, and — drawing on discussion at the Arthritis Healthcare Forum — outlines opportunities to strengthen transparency in meaningful ways for patients. At its core, this work reinforces that transparency should reduce burden to patients, improve understanding and help them make informed decisions about their healthcare.

Core Findings: The findings are clear and consistent: patients value transparency but too often experience it only after significant effort.

100% of patient advocates rate transparency as very or extremely important to their healthcare decisions

97% must advocate for themselves to receive clear information; only 1 in 43 never has to ask

86% must actively seek information rather than receive it proactively; only 14% describe their experience as very or extremely transparent

70% experienced delayed care as a direct result of unclear or missing information

44% have little to no confidence that they understand how their health data is shared or used

Patient Experience with Healthcare Transparency

March 2026 • n = 43 patient advocates

1.1 The Experience Gap

Patients consistently report that transparency is important, but it is rarely delivered in a proactive or accessible way.

Transparency experience today:

14% Very or extremely transparent (proactively informed)

51% Moderately transparent (must ask questions or look things up)

16% Slightly transparent (key details missing or unclear)

7% Not at all transparent

Advocacy frequency:

33% Always — almost always have to advocate strongly

23% Often — regularly push for information

35% Sometimes — need to ask clarifying questions

7% Rarely or never need to follow up

1.2 Adverse Outcomes from Poor Transparency

Gaps in transparency are not simply administrative challenges. They have real-world consequences for patient care, including delays, unexpected costs and reduced confidence.

70% Delayed care

63% Had to repeatedly follow up for information

58% Spent significant time understanding insurance

56% Received unexpected medical bills

42% Mistrust in providers or insurers

30% Confusion about treatment instructions

16% Duplicate tests or conflicting guidance

16% Felt pressured to consent without understanding

1.3 Administrative Burden

Patients are taking on a significant share of administrative work to navigate the healthcare system, especially in areas related to insurance and coverage.

Top time-consuming tasks (% selecting as a major burden):

65% Understanding insurance coverage or prior authorization requirements

56% Insurance calls or appeals

49% Completing forms or portals

40% Scheduling appointments

37% Billing questions

28% Tracking records across providers

26% Understanding test results

1.4 Patient Priorities and What Transparency Means

Clinical transparency is the primary explicit concern, but cost and insurance frustration dominates open-ended responses, suggesting that structured survey responses may not fully capture the extent of cost-related concerns expressed in open-ended responses.

72% Clear explanation of treatment options
53% Clear explanation of diagnoses
53% Knowing risks and side effects
51% Understanding expected out-of-pocket costs before receiving care
42% Clear communication after visits (notes, follow-ups)
26% Understanding why coverage decisions or denials happen

Note: "Knowing who has access to my data" was selected by only 2% in structured questions, yet data concerns were the most prominent theme in open-ended responses. Patients do not frame data privacy as "transparency" until explicitly prompted.

1.5 Technology, AI and Digital Navigation

Digital tool adoption is high but reflects gap-filling behavior rather than system integration. Patients are increasingly using digital tools, including AI and online resources, to better understand diagnoses, treatment options and test results, often to supplement gaps in clinical communication.

Digital tools in use:

93% Patient portals
79% Internet searches for health information
42% Online provider directories
37% Health apps
30% AI chatbots or symptom checkers
28% Online patient communities

Primary uses of AI or online tools:

63% Understanding diagnoses
63% Understanding test results
56% Exploring treatment options
49% Translating medical language
28% Preparing questions for appointments
19% Understanding costs or insurance coverage

1.6 Data Trust and Consent

Confidence in how health data is used is limited, with many patients expressing uncertainty about who has access to their information and how it is shared. Patients have high awareness of commercial data flows but low confidence in their own understanding and describe meaningful consent as largely absent.

Confidence in data use:

26% Completely or very confident
30%. Moderately confident
30%. Slightly confident
14%. Not confident at all

Believed to have access to health data:

98% Doctors and care teams
60% Third-party companies working with health systems
58% Automated systems or AI tools in healthcare
23% Marketing and social media companies

SECTION II — PATIENT VOICE

Direct Testimony from Survey Respondents

The following are direct quotations from patient advocates in response to open-ended survey questions.

> *"Nobody can ever tell you what it's gonna cost. What different people pay different things for the same thing."*
>
> **— Cost transparency**

> *"Solid, plain English explanations of health insurance coverage that is easy to find. It's ridiculously difficult to determine what exactly is covered by both the health plan and the prescription plan."*
>
> **— Insurance clarity**

> *"Insurance is absolutely my biggest pain point when it comes to medical transparency. Calling them has typically given me incorrect answers or no answer at all — especially when they deny prescription coverage and will ONLY communicate with my doctor's office, not with me."*
>
> **— Prior authorization and communication**

> *"Healthcare is too siloed, which makes it easy to not be transparent. A says talk to B and B says talk to A. Just someone listen."*
>
> **— Care coordination and fragmented records**

> *"Providing learning opportunities about conditions, without the push of advertisements from drug companies — and without being shared with them at all or any third party for marketing."*
>
> **— Data trust and commercialization**

> *"We have too many middle men that keep transparency from the patients."*
>
> **— Systemic friction**

> *"It would be nice if that transparency included Department of Veteran Affairs and Tricare Prime, which would assist veterans when making decisions on how to use their insurance."*
>
> **— VA and Tricare coverage gap**

> *"An increasing health literacy gap is contributing to less transparent medical care. Taking the time as physicians and care providers to properly inform your patient is as important as spending time with them in the appointment itself."*
>
> **— Health literacy and provider responsibility**

SECTION III — FEDERAL POLICY ANALYSIS

Legislative Intent vs. Patient Reality

The following analysis examines major federal transparency-related legislation and regulations against patient-reported outcomes from this survey. In each case, the policy was designed to address gaps that patients are still experiencing. These findings highlight a central challenge that while many policies focus on increasing transparency, they do not consistently ensure that information is understandable, accessible or actionable for patients.

Hospital and Payer Price Transparency Rules (2021–2023)

Patient Experience: 56% still received unexpected medical bills; 70% experienced delayed care due to cost confusion; cost opacity is the most prominent theme across all open-ended responses.

Policy Context: *CMS finalized hospital price transparency requirements in 2021 and payer price transparency rules in 2023, requiring machine-readable files and good-faith estimates. GAO and KFF audits document widespread non-compliance and limited consumer usability of published data. The No Surprises Act Good Faith Estimate provision applies in limited circumstances and carries low patient awareness.*

Key Questions: What implementation model would make price transparency functional at the point of patient decision-making, rather than machine-readable for compliance purposes only?

Prior Authorization Reform: CMS Interoperability & Prior Authorization Final Rule (2024)

Patient Experience: 65% cite prior authorization (PA) and insurance coverage understanding as their top time burden; 56% are managing insurance calls and appeals; patients report that insurers refuse to communicate PA decisions directly to them.

Policy Context: *CMS finalized the Interoperability and Prior Authorization rule in January 2024, requiring PA APIs, shortened decision timelines and reason codes for denials, with compliance timelines running through 2026–'27. State-level PA reform is advancing in over 30 states. The regulatory timeline will not provide relief for patients currently in the system.*

Key Questions: How should state and federal regulators accelerate patient-facing PA reform implementation, and what accountability mechanisms would close the gap between rule and reality?

21st Century Cures Act — Interoperability and Information Blocking Provisions

Patient Experience: 93% use patient portals, but 28% report tracking records across providers as a major time burden; siloed records generating duplicate tests and conflicting guidance cited directly in open-ends.

Policy Context: *Information blocking provisions effective 2021 and ONC's USCDI standards were designed to enable data portability. Portal adoption is high, but longitudinal care coordination remains elusive. OIG enforcement authority is limited; the gap between API availability and patient-facing interoperability persists.*

Key Questions: What patient-centered interoperability standards would move from technical API compliance to actual care coordination experienced by patients?

Inflation Reduction Act — Drug Price Negotiation and Beneficiary Transparency

Patient Experience: Pharmaceutical cost transparency is a top request in open-ended responses; patients describe inability to understand formulary tiers, coverage exceptions and why drugs are denied or switched.

Policy Context: *The IRA's Medicare drug price negotiation provisions are the most significant shift in pharmaceutical pricing policy in decades. However, patient-level cost clarity at the pharmacy counter — relative to their specific plan design — has not been addressed in implementation. Beneficiary education infrastructure has not kept pace with policy velocity.*

Key Questions: How should CMS build patient-facing tools that translate negotiated pricing into meaningful out-of-pocket information at the point of prescribing and dispensing?

AI in Coverage Decisions — CMS Proposed Rule (2024)

Patient Experience: 58% of patients believe AI or automated systems access their health data; patients express frustration with insurance companies overriding physician decisions; patients are unaware when algorithmic tools influence coverage determinations.

Policy Context: *CMS proposed a rule in 2024 requiring Medicare Advantage plans to ensure AI-driven utilization management tools do not substitute for individualized clinical review, including disclosure when automated tools are used. No equivalent standard applies to commercial insurers or Medicaid managed care.*

Key Questions: What disclosure, accountability, and appeal rights should attach to AI-driven coverage decisions across all payer types, and what role should states play in extending these protections?

Emerging Trends and Policy Considerations

PBM Reform — State Legislative Momentum

Patient Experience: Formulary tier structures, spread pricing and prescription denials without patient-facing explanation are direct sources of frustration in survey responses.

Policy Context: *Bipartisan PBM reform legislation has passed or advanced in over 20 states since 2022, targeting spread pricing, rebate pass-through, and formulary transparency. Federal legislation has stalled. A state patchwork is producing inconsistent patient protections.*

Key Questions: What minimum standard should apply nationally to PBM transparency for patients, and how should state insurance commissioners coordinate enforcement?

VA and TRICARE: The Military Patient Transparency Gap

Patient Experience: Multiple respondents named VA and Tricare as systems where federal transparency improvements do not apply or are not consistently implemented. This is a population with disproportionate chronic disease burden.

Policy Context: *Federal price transparency and prior authorization reform rules have varying applicability to VA and TRICARE. The Veterans Health Administration operates under a separate legislative framework; commercial Tricare plans are DOD-administered and exempt from several CMS rules.*

Key Questions: How should Congress and DOD address the transparency gap for military and veteran beneficiaries, and what models from civilian payer reform are most transferable?

Health Data Commercialization and Consumer Consent

Patient Experience: 44% have little to no confidence in how their data is used; 60% believe third-party companies access it; multiple patients cite data sold without meaningful consent as a specific harm.

Policy Context: *HIPAA does not prohibit the sale of de-identified health data. FTC enforcement against health data brokers represents the most active federal response. Washington, Nevada and Connecticut have enacted broader health data privacy statutes. A federal framework has not been enacted.*

Key Questions: What consent standards and data-use disclosure requirements should apply to commercial health data, and what enforcement mechanisms would make them meaningful to patients?

Health Literacy as a System Design Obligation

Patient Experience: 72% want clearer explanations of treatment options; open-ends consistently demand plain English across insurance, diagnoses and consent forms; the burden of understanding falls entirely on patients, not system design.

Policy Context: *Health literacy is increasingly framed as a systemic design challenge. The ACA requires plain-language SBCs; no equivalent standard applies to clinical communication, EHR patient-facing materials, or consent forms. AHRQ health literacy tools exist but are not mandated.*

Key Questions: What regulatory or incentive frameworks would make plain-language clinical and administrative communication a standard obligation rather than a best practice?

SECTION V — FORUM DISCUSSION

Key Themes and Perspectives

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5.1 Patient Expert Panel

Moderated by Hayley Dempsey, Federal Affairs Manager, Arthritis Foundation.

Panelists: Ela C. (IL), Christine C. (PA), Jennifer R. (FL), Candace R. (UT).

What "perfect transparency" would look like, according to patients:

- Proactive, clear information about costs, available supports, treatment options and timelines for any given condition or episode of care — delivered without requiring the patient to initiate
- Seamless transfer of medical records between providers and facilities. One panelist described a JA patient who went untreated from age 2 to 9 because a juvenile arthritis diagnosis was never communicated from the diagnosing specialist to the primary care physician
- Knowing exactly who to contact to resolve a problem, and receiving clear, timely explanations for the reasons behind delays and denials
- More shared decision-making and better coordination across specialties, rather than patients serving as the connective tissue between their own providers
- Policy language and plan documents written at a 3rd-grade reading level — not legalese that requires expert interpretation
- A reliable feedback loop: when a patient calls a doctor's office with information, there should be accountability that it reaches the right person and is acted upon
- Advance notice of prior authorization requirements so patients have sufficient time to complete benefit verification before a prescription or plan year expires
- Longitudinal access to patient records — easy visibility into what treatments have been tried and failed, even decades in the past, without having to reconstruct a medical history from memory

The defining quote from the patient panel:

> *"I want to be able to forget I have the disease day to day."*
> **— Patient panelist describing what good coverage looks like**

In context, this quote captures a standard that goes beyond transparency as disclosure: It describes a coverage experience so seamless that the patient's chronic disease does not dominate their daily life. It means not being on the phone with insurers, not fighting denials, not experiencing the mental or physical toll of treatment delays. The panel converged on this as the aspirational test for whether transparency is working.

5.2 Policy/Industry Expert Panel

Moderated by Alisa V. Casavant, Senior Director of Policy, Arthritis Foundation.

Panelists: Melissa Bartlett (ERIC), Paige Colston (American College of Rheumatology), Robert Tennant (WEDI), J.P. Wieske (Monument Advocacy).

Key themes from the policy expert discussion:

- **"Transparency for transparency's sake is stupid."** The panel was direct: Transparency must be complete, timely and meaningful. Disclosure that is technically compliant but functionally opaque serves regulators, not patients.
- **Price transparency infrastructure is imperfect.** The data requirements from the 2021 Consolidated Appropriations Act were described as very imperfect; they need to be improved and simplified before they can serve individual patients rather than sophisticated purchasers.
- **Real-time benefit tools exist but are inaccessible.** There is a real-time benefit tool standard through NCPDP, but most providers do not have access to it. The panel identified the need to move past issues of data ownership and liability toward an open-source, real-time benefit capability for patients with clear accountability for who builds, operates and maintains it.
- **Blue-sky ideas for structural reform.** The panel discussed aligning the long-term interests of patients and payers; focusing resources on identifying the single most helpful tool for patients rather than pursuing multiple partial solutions; building incentive structures that reward trust; and confronting the financing challenge posed by innovations like gene therapies that cost millions of dollars.

SECTION VI — RECOMMENDATIONS

Policy and Practice Recommendations

Drawing on patient survey findings, expert panel discussion, and AHF testimony

6.1 Adopt "I Want to Forget I Have This Disease" as the Standard for Success

The Forum surfaced a powerful, patient-defined standard for what good looks like: a coverage experience so seamless that chronic disease does not dominate daily life. This should serve as the north star for evaluating transparency reforms — not whether information was disclosed, but whether patients can live their lives without fighting the system.

> **Recommendation:** The Arthritis Foundation should adopt this framing as its organizing principle for transparency advocacy and use it as a benchmark when evaluating federal and state transparency policy proposals.

6.2 Identify and Address the Biggest Trust Pain Points

Trust emerged as the key barrier to progress. Patients do not trust that information will reach the right person, that denials are based on clinical evidence, that their data is being used appropriately, or that their input shapes policy outcomes. The expert panel reinforced that transparency without trust is compliance theater.

> **Recommendation:** The Arthritis Foundation should conduct a targeted trust audit — mapping the specific points in the patient journey where trust breaks down (e.g., prior authorization communication, insurer call center accuracy, consent form comprehension, records transfer) and developing intervention strategies for the highest-impact failure points.

6.3 Explore Collaborative Models Where Patient-Payer Interests Are Aligned

The Forum identified areas where patient and payer interests naturally align — for example, both parties benefit from avoiding joint replacement surgery by achieving medicated remission earlier. These shared-interest zones represent opportunities for collaborative transparency models that are less adversarial than the current framework.

> **Recommendation:** The Arthritis Foundation should convene a working group with willing payer partners to develop a collaborative transparency pilot in at least one area of aligned interest (e.g., early intervention in OA/RA to prevent surgical escalation), documenting what patient-payer transparency collaboration looks like when both parties have a stake in the outcome.

6.4 Identify the "One Tool That Could Be Most Helpful" and Drive Adoption

Rather than pursuing comprehensive reform across all transparency domains simultaneously, the expert panel advocated for a more focused strategy: Identify the single highest-impact tool for patients and concentrate resources on adoption. The real-time benefit tool (RTBT) standard through NCPDP was cited as one candidate, but adoption remains low because most providers lack access.

> **Recommendation:** The Arthritis Foundation should work with partners to evaluate candidate tools (RTBT, standardized cost estimator, PA status tracker) and identify the one with the highest potential patient impact and feasible adoption pathway. Develop an incremental adoption strategy that includes incentive structures for providers and payers, and advocate for federal or state mandates if voluntary adoption does not materialize within a defined timeframe.

6.5 Federal Transparency Enforcement and Implementation

Price transparency rules are producing compliance artifacts, not patient comprehension. The expert panel described the 2021 Consolidated Appropriations Act data requirements as "very imperfect." Patient survey data confirms that 56% still receive unexpected bills despite multiple federal mandates.

> **Recommendation:** Advocate for simplification and patient-usability testing of federal price transparency requirements. Support enforcement that measures patient comprehension outcomes, not just institutional disclosure compliance. Engage CMS on the gap between machine-readable file publication and point-of-care cost clarity.

6.6 Prior Authorization: Close the Communication Gap

Patient panelists described a system where PA denials are communicated only to the prescribing physician's office, not to the patient. Patients reported having no advance notice that PA is required, leaving insufficient time to complete benefit verification before prescriptions or plan years expire.

> **Recommendation:** Advocate at the state and federal level for requirements that PA decisions be communicated directly to patients, not only to providers. Support advance-notice requirements that give patients meaningful time to navigate PA processes. Continue supporting gold-carding programs and state legislation that reduces PA volume for high-approval services.

6.7 Data Infrastructure: Move Toward Open-Source, Real-Time Benefit Capability

The expert panel identified the core data infrastructure problem: real-time benefit tools exist (NCPDP standard) but most providers lack access. Issues of data ownership and liability are blocking progress toward an open-source, patient-facing capability.

> **Recommendation:** Support federal and industry efforts to expand RTBT access to all providers and patients. Advocate for resolution of data ownership and liability barriers that prevent open-source benefit tool development. Engage WEDI and standards organizations on implementation pathways that prioritize patient-facing usability.

6.8 Health Literacy and Plain Language

Patient panelists called for policy language at a 3rd-grade reading level. The demand for plain English was the single most consistent theme across both panels and the pre-Forum survey.

> **Recommendation:** Advocate for plain-language requirements to be extended beyond the ACA's Summary of Benefits and Coverage to include clinical communication, consent forms, PA decision letters, and EHR patient-facing materials. Support development of standardized, plain-language templates that plans and providers can adopt.

6.9 For the Arthritis Foundation

The Forum demonstrated the power of connecting patient experience data directly to policy analysis. The AF is positioned to lead a model where patient testimony and survey data are not illustrative, they are the evidence base.

> **Recommendation:** Publish this report and distribute to state insurance commissioners, CMS and congressional health committees. Use the "forget I have this disease" framing as a campaign anchor for 2026–2027 advocacy. Develop the trust audit and collaborative pilot recommendations above as concrete 2026–2027 deliverables with named owners and timelines.

Longer-term strategic considerations:

- Incrementalism as strategy: The expert panel endorsed a focused approach over comprehensive reform. Identifying the single highest-impact intervention and driving adoption may yield more measurable progress than pursuing simultaneous action across all transparency domains.
- Patient-payer alignment zones: Further exploration of conditions and care episodes where payer and patient interests naturally converge (e.g., avoiding surgical escalation through earlier treatment) could produce collaborative models that bypass adversarial dynamics.
- Financing innovation: The expert panel raised the unresolved challenge of financing high-cost innovations like gene therapies within a transparency framework. This will require separate policy engagement beyond the scope of current transparency reform.