2026

Optimizing Clinical Trial Participation: Addressing Social and Financial Factors

Roundtable findings and recommendations

PAN Foundation

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Contents

LETTER FROM OUR LEADERSHIP

Dear colleagues,

In October 2024, the Patient Access Network (PAN) Foundation, a national nonprofit organization dedicated to accelerating access to affordable, equitable healthcare for people with serious and chronic illnesses, launched our Opening Doors to Clinical Trials initiative, a program designed to expand equitable access to clinical research by providing education and support resources to increase participation and representation in clinical trials.

Representation in clinical trials is critical for improving equitable health outcomes. With that in mind, PAN launched this education initiative to empower people with comprehensive tools and resources to navigate the complexities of clinical trials, including those who have felt left out or overlooked. The program has several differentiating components, including one-on-one support, an easy-to-navigate trial finder, and person-centric content.

However, since the program's launch, it has become clear that clinical trial access is not solely a matter of awareness and education. Instead, we found many patients face social and non-medical challenges and financial barriers to participation – problems that require coordinated solutions across the research industry.

On October 23, 2025, the PAN Foundation hosted Optimizing Clinical Trial Participation: Addressing Social and Financial Factors in Atlanta, GA. By hosting this roundtable, the PAN Foundation reinforced its commitment to moving beyond awareness-building toward implementation-ready solutions. The discussion aligns with PAN's broader mission of addressing access, affordability, and equity challenges before they become barriers to care.

This convening represents an early but critical step in the Opening Doors to Clinical Trials program's long-term vision: transforming clinical research into a more inclusive, patient-centered, and sustainable enterprise through durable partnerships and system-level changes.

PAN looks forward to continuing cross-sector collaboration to advance many of the recommendations in this report. We hope you'll join us in opening doors for all people to clinical trials, regardless of their social or financial challenges.

Kim Baich
Chief Impact Officer
PAN Foundation

Executive summary

On October 23, 2025, the PAN Foundation convened a cross-sector roundtable in Atlanta, Georgia—Optimizing Clinical Trial Participation: Addressing Social and Financial Factors—as part of its Opening Doors to Clinical Trials initiative. The convening brought together leaders from pharmaceutical, clinical research, patient advocacy, and community-based organizations to examine how social drivers of health (SDOH) and financial barriers shape access to and participation in clinical trials. Discussions reinforced a central theme: clinical trial access is not solely a scientific or operational challenge, but patient affordability and systems-design issues.

Social and financial realities—such as transportation limitations, employment insecurity, caregiving responsibilities, housing instability, digital access gaps, language barriers, and mistrust—often determine who can participate, remain enrolled, and benefit from research. Despite being labeled “no-cost,” trials frequently impose significant out-of-pocket expenses, lost income, and financial risk that disproportionately exclude low-income individuals, rural communities, older adults, and populations of color.

Across three sessions, roundtable participants identified critical gaps in current trial models, underscoring that equitable clinical trial participation cannot be achieved through incremental or late-stage fixes. Through the participant discussions, key themes emerged including persistent financial and infrastructure gaps as the primary barriers to inclusive enrollment, emphasizing the need to shift investment upstream toward site readiness, community engagement, and enrollment infrastructure.

There was strong and resounding consensus that diversity and social determinants of health must be embedded at protocol inception, rather than retrofitted after enrollment challenges arise, and that trial-agnostic approaches are needed to drive consistency across portfolios. The discussion also highlighted the urgent need to modernize the culture and language of clinical research, moving away from technical, inaccessible communication toward clear, patient-centered education delivered well before trial participation is required.




The roundtable produced actionable recommendations to address these challenges. These include:

Elevate the patient voice in trial design

Integrate structured patient input early in protocol development to identify financial, logistical, and regulatory barriers before trials launch, and advocate for policy modernization to reduce participation constraints.

Move beyond simple reimbursement models

Replace narrow reimbursement approaches with comprehensive, needs-based support that addresses transportation, caregiving, and administrative barriers, including insurance navigation and patient assistance guidance.

Proactively integrate SDOH into protocol design

Embed social determinants of health considerations (SDOH) at protocol inception by engaging community-based providers and organizations and establishing partnerships to connect patients with essential support resources.

Educate and equip the healthcare ecosystem

Expand clinical trial education for providers, care teams, and trusted community messengers, ensuring fair compensation for provider engagement and culturally relevant education for patients and caregivers.

Commit to collaborative, sustained investment

Advance health equity through long-term, cross-industry partnerships with community organizations and scalable, compliance-friendly investments that support patient engagement beyond individual trials.

Looking ahead, participants emphasized the need to move beyond episodic, transactional approaches toward an integrated operating model for inclusive clinical research—one that is financially transparent, operationally proactive, culturally responsive, and grounded in long-term partnerships.

Advancing equity in clinical trials was framed not only as a moral imperative, but as essential to scientific validity, operational efficiency, and the future sustainability of clinical research.

Roundtable background

Social drivers of health and financial barriers

Social drivers of health play a decisive role in whether individuals can realistically participate in clinical trials. While eligibility criteria focus on clinical factors, participation is often determined by social, economic, and structural conditions that shape a person's ability to engage with research over time.

As part of PAN's Opening Doors to Clinical Trials initiative, ComPANion Access Navigator field phone calls from the public seeking clarity and support around clinical trial participation.

Of the calls serviced by the ComPANions since the initiative's launch, 87 percent of calls were around SDOH needs versus clinical support.






ROUNDTABLE BACKGROUND, CONT.

Overall, these factors influence awareness of trials, willingness to enroll, and the ability to remain in the trial. They include:

Transportation and geographic access

Many trials are conducted at academic medical centers or urban research sites that are far from where patients live. Lack of reliable transportation, long travel times, limited public transit, and parking costs can make frequent study visits impractical, particularly for rural residents, older adults, and people with disabilities.

Time constraints and employment insecurity

Clinical trials often require multiple visits, lengthy appointments, and rigid scheduling. Participants who work hourly jobs, hold multiple jobs, or lack paid leave may face lost wages or risk job loss when attending study visits. Caregiving responsibilities further constrain available time.

Housing instability and residential mobility

Individuals experiencing housing insecurity or frequent moves may struggle with consistent communication, appointment adherence, and long-term follow-up. Stable housing is often an unspoken prerequisite for trial participation, even when not formally stated.

Digital access and health literacy

Trials increasingly rely on electronic consent, patient portals, wearable devices, and telehealth. Limited broadband access, lack of devices, or low digital literacy can exclude otherwise eligible participants. Similarly, complex consent forms and study materials can be difficult to navigate without adequate health literacy support. This is especially true in rural communities.

Language, culture, and trust

Limited English proficiency and lack of culturally responsive engagement can deter participation. Historical and ongoing experiences of discrimination in healthcare and research have fostered mistrust among many communities, particularly communities of color, immigrants, and rural populations. Without trusted messengers and culturally aligned communication, recruitment efforts often fall short.

Caregiving and family responsibilities

Participants who care for children, elders, or family members with disabilities may be unable to attend visits without childcare or respite support. These responsibilities are rarely addressed in trial design.

ROUNDTABLE BACKGROUND, CONT.

In addition to social drivers of health, there are also financial barriers at play. Although clinical trials are often described as “no-cost” or “free,” participation frequently imposes substantial out-of-pocket and indirect financial burdens.

For many households, the financial risk of lost income outweighs the perceived benefit of trial participation. Financial considerations include:

Direct out-of-pocket costs

Participants may incur expenses related to transportation (gas, rideshare, public transit, parking), meals during long visits, lodging for trials requiring travel or overnight stays, and ancillary medical costs not covered by the study sponsor (e.g., standard-of-care procedures, copays, deductibles).

Lost income and opportunity costs

Uncompensated time away from work is one of the most significant barriers to participation. This includes lost wages for hourly or contract workers, use of limited paid time off, and reduced productivity for self-employed individuals.

Insurance-related uncertainty

Participants may fear unexpected medical bills, coverage denials, or impacts on future insurance eligibility. Confusion around what costs are covered by the sponsor versus the insurer often leads patients to decline participation altogether.

Upfront cost burdens

Reimbursement for trial-related expenses is frequently provided after costs are incurred. For individuals living paycheck to paycheck, the inability to front travel or lodging costs can be a decisive barrier, even when reimbursement is promised.

Inadequate or inequitable compensation

Participant stipends may not reflect the true time, effort, and financial burden required by the study. Flat compensation structures can disproportionately disadvantage participants who travel farther, require more time off work, or need additional support services.

Roundtable objectives

Because clinical trial participation is shaped as much by social and financial realities as by medical eligibility, it is essential to address social drivers of health and financial barriers in hopes of including the very populations most affected by disease. Therefore, the roundtable was designed with two primary objectives:

1. Develop actionable strategies to address financial and social barriers to clinical trial participation.

Discussions focused on generating practical, field-informed recommendations that sponsors and research partners can operationalize to improve access, efficiency, and equity in clinical trial design and execution.

2. Center the patient perspective in shaping future clinical research practices.

The convening prioritized lived patient experience, ensuring that financial, social, and logistical barriers are not treated as downstream execution issues, but as core inputs into decision-making and trial models.

Roundtable participants

To achieve these objectives, PAN brought together representatives with cross-sector expertise in clinical trials. Participants included senior leaders with deep knowledge and experience in trial operations, health equity, real-world evidence, patient advocacy, and community engagement from the following companies and organizations:

- **Amgen,** Representation in Clinical Research
- **Building Constellations, LLC,** Patient advocacy
- **Bristol Myers Squibb,** Clinical Operations
- **Cosmos Clinical,** Clinical Site Management and Services
- **Emory University,** Goizueta Alzheimer's Disease Research Center
- **EmVenio Clinical Research,** Business Development
- **Faces of Research,** Community Activation Recruitment and Engagement
- **HCN Global,** Patient Advocacy
- **Jumo Health,** Health Equity
- **Merck**, Clinical Operations and Medical Affairs
- **Pygmalion Health,** Healthcare Advisory
- **Randomize Now,** Community Engagement
- **RedKola Digital Lab,** Product Management
- **Renew Health Clinical Research, LLC,** Diverse Patient Recruitment
- **Sanofi,** Clinical Trial Diversity and Inclusion
- **Takeda Pharmaceuticals,** Trial Equity and Representation
- **Thermo Fisher Scientific**, Strategic Site Collaborations
- **Walgreens Clinical Trials,** Real World Evidence

Roundtable format and structure

The roundtable's design centered on structured, solutions-oriented dialogue to surface practical insights and actionable recommendations for addressing social and financial barriers to clinical trial participation. To ensure depth of discussion, the meeting moderator facilitated three distinct but interrelated sessions.

Each session focused on a critical dimension of the clinical trial participation experience, combining expert perspectives with real-world, community-informed insights. Discussions encouraged cross-sector exchange among stakeholders representing patient advocacy, community-based organizations, healthcare delivery, research operations, and policy.

Across all three sessions, participants placed an emphasis on identifying scalable strategies that could be integrated into trial design, sponsor practices, and community engagement models. Key insights and recommendations captured throughout the discussion informed both near-term actions and longer-term systemic change.

The sections that follow summarize the focus of each session, along with the core insights and actionable ideas that emerged from the dialogue.

Session outcomes

Session 1: The financial strain of clinical trial eligibility

The first session focused on identifying the financial and structural barriers that shape clinical trial participation before enrollment occurs. Grounded in lived patient experience and frontline operational realities, this discussion surfaced the often-invisible costs associated with eligibility requirements, including diagnostic testing, disease confirmation, baseline assessments, and ongoing standard-of-care treatment. Participants emphasized that these pre-enrollment burdens, while rarely accounted for in trial budgets or protocols, play a decisive role in determining who is able to qualify for participation.

Key insights

Consistent with the roundtable's emphasis on problem identification, panelists highlighted a complex ecosystem of financial, logistical, and regulatory constraints that patients must navigate prior to consent. Challenges related to compensation reporting requirements, restrictions on incentivized payments, transportation access, caregiving responsibilities, and administrative complexity were cited as recurring barriers. Participants agreed that narrowly defined reimbursement strategies—such as covering travel or meals—fail to address the full range of factors influencing eligibility and sustained participation.

Participants formed consensus that social determinants of health must inform protocol design from the outset, rather than being addressed reactively in response to enrollment challenges. They also identified gaps in provider awareness and limited time for trial-related discussions as critical bottlenecks, underscoring the need for upstream, system-level interventions.

Actionable ideas

Reflecting the roundtable's solutions-oriented approach, participants advanced the following actionable strategies:

- **Integrate structured patient and community review** into protocol development to identify barriers early and simplify participation requirements.
- **Advocate for policy and regulatory modernization** related to patient compensation and reporting requirements.
- **Move beyond basic reimbursement** by supporting ancillary needs—such as transportation coordination, childcare access, and insurance navigation—through patient-facing platforms.
- **Engage community-based healthcare providers and community-based organizations** during protocol design to ensure alignment with real-world patient circumstances.
- **Compensate physicians for the time required to educate patients** about clinical trials and participation options.
- **Invest collaboratively with community organizations** already delivering high-impact, cost-effective support services.

Session 2: Financial implications of clinical trial participation — Stipends: support or sacrifice?

Building on the first session's focus on eligibility and early access, the second session examined the financial realities patients face during active trial participation. The discussion centered on whether existing stipend and reimbursement models meaningfully mitigate financial burden or inadvertently shift costs onto participants and their families.

Panelists emphasized that flat-rate compensation structures rarely reflect the true economic impact of participation across diverse patient circumstances.

Key insights

Participants described how trial participation can result in lost wages, increased caregiving expenses, transportation burdens, and longer-term economic tradeoffs. These challenges are often compounded by tax implications, including 1099 reporting thresholds, and concerns that compensation may jeopardize eligibility for public assistance programs. Such uncertainties were identified as deterrents to both enrollment and retention.

Aligned with the roundtable's emphasis on continuity and implementation, the discussion underscored that patient support must extend beyond isolated study visits and account for household-level and quality-of-life impacts. Meaningful engagement was framed as sustained support across the trial lifecycle rather than episodic interaction.

Actionable ideas

To advance more equitable and operationally feasible compensation models, participants recommended:

- **Transition from flat-rate stipends to itemized, needs-based reimbursement** models that reflect actual participant expenses.
- **Establish clear, transparent guidance on allowable expenses** to reduce confusion and financial risk for participants.
- **Pilot regional compensation frameworks** that account for cost-of-living differences.
- **Extend patient engagement and support beyond trial completion** to promote continuity of care and address ongoing needs.
- **Partner with local organizations, managed care entities, and disease-specific programs** to provide wraparound support services.
- **Embed health equity considerations,** community needs assessments, and localized data into protocol development to personalize participation pathways.

Session 3: The impact of social determinants of health on clinical trial access

The third session expanded the discussion to a system-wide lens, examining how social determinants of health—including socioeconomic status, geography, education, housing stability, and digital access—shape who is able to participate in clinical research.

Consistent with the roundtable's framing, panelists emphasized that inequitable access reflects design and operating model failures rather than shortcomings in recruitment tactics alone.

Key insights

Participants stressed that advancing equity requires a shift from reactive problem-solving to proactive, system-wide planning. Technology access and digital literacy emerged as persistent barriers, particularly as trials increasingly rely on electronic consent, remote monitoring, and virtual engagement tools. Trust was also identified as foundational, with panelists noting that historical and ongoing experiences with research institutions strongly influence community willingness to engage.

Accountability emerged as a unifying theme across sessions. Participants emphasized that traditional research sites must be held responsible for inclusive enrollment outcomes, while community-based sites require sustained investment to build the infrastructure and operational capacity needed to support participation.

Actionable ideas

To translate these insights into actionable change, participants recommended:

- **Requiring social determinants of health assessments** during pre-screening to tailor participant support strategies.
- **Including technology onboarding** and ongoing digital support as standard components of trial participation.
- **Investing in long-term, bi-directional community engagement** grounded in listening, partnership, and shared accountability.
- **Collaborating with trusted "bridge" organizations** that can serve as intermediaries between sponsors and communities.
- **Engaging community-based sites well in advance** of trial launch to assess readiness and infrastructure needs.
- **Implementing dashboards and analytics to track SDOH-related patterns**—such as missed visits, delayed labs, or digital attrition—and using these insights to inform real-time protocol modifications.

Emerging themes

In summarizing the roundtable sessions, clear themes became apparent.

Financial and infrastructure gaps must be addressed directly

Funding constraints were identified as the single greatest barrier to equitable enrollment and site performance. Limited sponsor budgets and under-resourced research sites—particularly newer and frontier sites—create structural inefficiencies that cannot be solved through execution alone.

Shifting resources upstream—toward awareness, enrollment readiness, and site infrastructure—was viewed as essential to improving trial timelines, participation, and overall return on investment.

Diversity and social determinants of health must be embedded at protocol inception

Retrofitting inclusion strategies late in development was widely viewed as ineffective and costly. A future-ready approach requires building relationships with community-based sites years in advance, incorporating standardized tools to assess community barriers, and ensuring protocols reflect real patient needs.

Importantly, participants stressed the need for trial-agnostic solutions that drive consistent practices across therapeutic areas, rather than isolated, study-by-study interventions.

The culture and language of clinical research must evolve

The industry's reliance on technical, inaccessible language continues to limit public understanding and engagement. Participants committed to more direct, authentic communication and drew a powerful parallel to CPR training: just as communities are prepared for emergencies before they occur, patients and caregivers should have access to baseline education that enables confident participation in research when the need arises.

Education about clinical trials is essential

Clinical trial education across all healthcare sectors—and directly with patients and communities—is essential to increasing both participation and representation in research. Consistent, sector-wide education equips clinicians, care teams, community organizations, and patient advocates with a shared baseline understanding of how trials work, who can participate, and what protections and supports exist.

When education is delivered through trusted messengers and integrated into routine care and community settings—rather than confined to research sites—it normalizes clinical research as a care option, reduces informational barriers, and creates more equitable pathways for historically underrepresented populations to engage in and benefit from clinical trials.

Key recommendations

Elevate the patient voice in trial design

Patients encounter financial, logistical, and regulatory barriers that are often invisible during protocol development, including compensation reporting requirements and restrictions on incentivized payments. Clinical trial protocols must be informed by lived patient experience to identify participation barriers before trials launch.

It is essential to integrate structured patient review into protocol development to surface barriers and identify opportunities for simplification early. It is also important to engage in advocacy efforts to modernize regulatory and policy frameworks related to patient participation and compensation.

Move beyond simple reimbursement models

Access to medication and trial participation is constrained by more than direct costs; logistical hurdles and caregiving responsibilities frequently determine feasibility. Support models must address the full ecosystem of patient needs, not just travel or meal reimbursement.

Recommended actions included developing patient-facing platforms that allow participants to coordinate transportation, secure childcare, and access ancillary support services, as well as integrating clear guidance on insurance navigation and patient assistance programs to reduce administrative burden and confusion.

Proactively integrate SDOH into protocol design

Social determinants of health are often considered too late in the trial lifecycle, resulting in reactive and costly workarounds. Therefore, SDOH considerations should be embedded at protocol inception to ensure trials reflect real-world patient circumstances.

This includes involving community-based healthcare providers and community-based organizations during protocol development to align trial requirements with patient realities, as well as establishing partnerships that connect patients to SDOH-related resources that sponsors cannot directly fund.

KEY RECOMMENDATIONS, CONT.

Educate and equip the healthcare ecosystem

According to PAN data, patients – even those from historically underrepresented communities – are interested in clinical trials, trust their healthcare provider, and look to them as a valuable source for research opportunities. However, only one in five patients have had a conversation with their healthcare provider around clinical trials. Limited provider awareness and time constraints reduce patient access to accurate, timely information about clinical trials.

Reaching out to the provider community with support resources and continuing medical education around how to start a conversation with patients around clinical trials will help open more doors to research opportunities. However, we must provide fair compensation to physicians for time spent discussing clinical trials and educating patients.

Community engagement work is also essential for education. We must train community leaders and local trusted messengers to deliver culturally relevant, accurate information to patients and caregivers around clinical trials.

Commit to collaborative, sustained investment

Health equity in clinical research cannot be achieved by individual organizations acting alone or through short-term initiatives. Cross-industry collaboration and sustained investment are required to scale effective solutions.

Sponsors should identify and partner with community organizations already delivering high-impact, cost-effective support services and explore partnerships to provide non-incentivized, compliance-friendly resources (e.g., health devices) that support patient engagement without regulatory risk.

Participant perspectives

"The future of equitable care begins with clinical trial diversity. The PAN Foundation is helping to make that possible."

Nzinga Lowe, *CEO and Founder (Pygmalion Health)*

"An inspiring and insightful experience that fostered meaningful dialogue, encouraged collaboration, and offered practical, educational takeaways for real world impact."

Bukola Adeosun, *Sr. Manager, Inclusive Operations & Business Solutions (Amgen)*

"The roundtable provided a valuable platform to engage with peers from across the pharmaceutical industry, academia, and other sectors on the most pressing issues facing our field. I left the discussion feeling inspired and confident that the insights shared at this event will help drive meaningful change."

Angel Akinbinu, *Director, Trial Equity & Representation (Takeda Pharmaceuticals)*

"Grateful to contribute to a collective effort focused on removing barriers for patients and advancing better science, safer therapies, and equitable outcomes."

Zoe Felicie-Jones
Sr. Project Manager - Strategic Site Collaborations (Thermo Fisher Scientific)

PARTICIPANT PERSPECTIVES, CONT.

"It was an amazing experience and honor to have a seat at the table. A table where like minds discuss the possibilities of creating an equitable industry that goes beyond the realm of what if, but committing ourselves to reaching beyond so it becomes reality."

Mel Hardman, *Founder (Faces of Research)*

"Great collaborative group dedicated to scalable solutions, inspiring day."

Kristin Tolbert, *Assistant Vice President, Health Equity (Jumo Health)*

"As long as we continue to advocate for equity, we will make an impact."

Anjanette Elligan, *Senior Site Partnership Lead*

"One size does not fit all when it comes to clinical trials. Community engagement needs to start before the trial begins, the voice of the patient should come in early."

Ngozi Afulezi, Consultant (RedKola Digital Lab)

Conclusion

The current, largely transactional approach to clinical trial engagement is insufficient for the complexity and urgency of today's research environment. What is required is a sustained, systems-level operating model—one that aligns sponsors, sites, patient organizations, and communities around a shared, long-term vision for access, efficiency, and trust.

Building trials that reflect real patient lives is essential not only for equity, but for scientific validity, operational efficiency, and long-term sustainability. Moving forward, success will depend on the industry's ability to transition from episodic engagement to a durable, systems-level model rooted in trust, transparency, and shared accountability. Participants emphasized that this roundtable convening should mark the beginning of an enduring partnership, not a one-time dialogue.

Leading with solutions

While the industry has long recognized the importance of diversity, equity, and social drivers of health, progress will require moving beyond conversation and into sustained action. PAN is committed to helping shift the field from identifying challenges to operationalizing solutions—embedding practical supports into the fabric of clinical trial design and delivery.

Looking ahead, the PAN Foundation's immediate next step is to partner with roundtable participants to translate these insights into a practical, industry-facing resource. This effort will result in the development of a clinical trial access "playbook" that outlines actionable strategies for addressing social drivers of health and financial barriers to participation. Designed for broad distribution across the clinical research ecosystem—including sponsors, research sites, and community partners—the playbook will provide tangible tools, guidance, and referral pathways that organizations can use to support participants.

In parallel, PAN will continue to convene roundtable participants and additional stakeholders to further develop and refine the ideas that emerged from this discussion. These ongoing convenings will serve as a collaborative forum for shared learning, innovation, and alignment, ensuring that solutions are informed by real-world experience and remain responsive to evolving patient and site needs.
This next phase may take the form of a formal coalition—bringing together sponsors, sites, patient organizations, and community-based partners around a shared commitment to improving access and equity in clinical research.

Ultimately, PAN's goal is to lead a movement dedicated to addressing the social and financial barriers that limit clinical trial participation, embedding these priorities into standard research practice and advancing a more inclusive, patient-centered future for clinical research.

About the PAN Foundation

As a leading charitable foundation and healthcare advocacy organization, the PAN Foundation is dedicated to accelerating access to treatment for those who need it most and empowering patients on their healthcare journeys. We provide critical financial assistance for treatment costs, advocate for policy solutions that expand access to care, and deliver education on complex topics—all driven by our belief that everyone deserves access to affordable, equitable healthcare.

Since 2004, our financial assistance programs have helped more than 1.2 million people to start or stay on life-changing treatment. In addition, we've achieved major policy victories that increase access to care, mobilized patient advocates to call for change, and educated people nationwide on critical healthcare-related topics. We're committed to working towards a future where equitable health outcomes are a reality for all.

Learn more by visiting us at **panfoundation.org**.

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Improving access.
Transforming health.