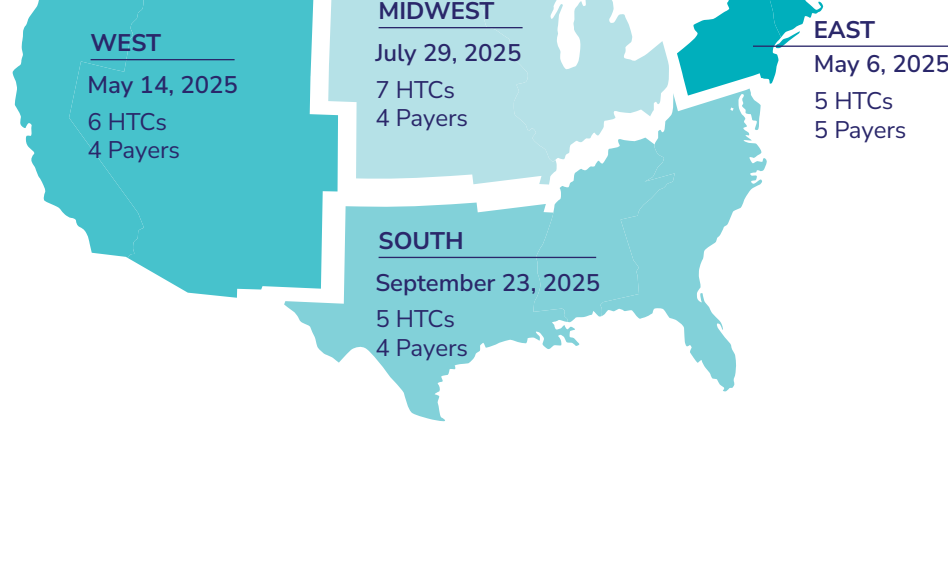


Payer-Provider Alignment to Advance Comprehensive Care for Bleeding Disorders

In 2025, the National Bleeding Disorders Foundation's Comprehensive Care Sustainability Collaborative (CCSC) convened four regional payer/provider working groups to explore collaborative strategies that support high-quality, cost-effective care for individuals with bleeding disorders.



Key Insights



Regional Characteristics

- High concentration of HTCs with strong regional availability
- Elevated payer awareness of HTCs as centers of excellence
- Limited payer understanding of differences between hemophilia drug classes
- Concerns around the future cost burden of gene therapies



Current Challenges

- Misalignment between payer coverage/utilization criteria and best clinical practice
- Lack of structured communication channels between payers and HTCs
- High administrative burden from prior authorization and step therapy policies



Opportunities for Collaboration

- Enhance payer education on hemophilia drug classes and gene therapy pipeline
- Improve integration between HTC services and payer care management
- Facilitate data sharing to demonstrate HTC value and support access decisions

EAST

May 6, 2025

5 HTCs

5 Payers



Participant Quotes

“I’m excited by the interest in developing coverage guidelines for payers through MASAC.”

- HTC Provider

“It’s a continual dialogue for us to justify those higher-cost treatments to employers.”

- Regional Payer Medical Director



Regional Characteristics

- Western and Mountain states have the fewest HTCs across the largest geography
- HTCs frequently manage patients across state lines
- Strong payer interest in HTC-led strategies to reduce product waste



Current Challenges

- Medical vs. pharmacy benefit misalignment increases complexity for HTC-administered therapies
- HTC administrative staff are often unfamiliar with payer-specific PA requirements
- Inconsistent coverage for patients switching from factor to non-factor therapies



Opportunities for Collaboration

- Adjust payer policies to reduce administrative burden for multi-state care
- Create shared data standards between HTCs and payers
- Assess and refine utilization management policies to avoid care delays

WEST

May 14, 2025

6 HTCs

4 Payers



Participant Quotes

“Being cognizant of the specific data that payers want might help HTCs provide the right support to ensure services get to patients.”

- HTC Provider

“If there are burdens that can be avoided, that’s the low-hanging fruit just to get the patients the care they need.”

- Regional Payer Pharmacy Director



Regional Characteristics

- A greater willingness to collaborate with HTCs and align policy decisions with specialist input, reflecting stronger support for multidisciplinary care models
- There is a continued need for education and data to help explain the full scope of services HTCs provide and justify high-cost claims
- Geographic disparities remain a challenge, with rural areas in experiencing limited access to HTC services and specialty care



Current Challenges

- Step therapy and fail-first policies potentially lead to harmful bleeds before access to appropriate therapy
- Short reauthorization intervals create an administrative burden and threaten the continuity of care
- High-cost claims, particularly in self-funded employer plans, are under heightened scrutiny, placing pressure on payers
- Limited payer awareness of HTC services and the unbilled proactive care, which results in undervaluation of the HTC model
- Centralized specialty pharmacy distribution may delay emergency treatment, especially in rural or remote areas
- Evolving epidemiology of inhibitors complicates treatment planning
- Fragmentation across medical and pharmacy benefits leads to misalignment in coverage decisions
- Documentation of bleeds is inconsistent, making it hard to meet coverage criteria



Opportunities for Collaboration

- Align payer policies with HTC clinical expertise to ensure safe, individualized treatment
- Support integration of pharmacists and technicians in HTC teams to optimize adherence and dose tracking
- Expand education to improve payer understanding of HTC services
- Coordinate across medical and pharmacy benefits to streamline access
- Establish shared protocols for surgery and emergencies to reduce ER visits and hospitalizations
- Improve recognition of 340B reinvestment into non-billable, cost-saving patient services
- Develop data-sharing strategies to demonstrate the value of HTC-based care

MIDWEST

July 29, 2025

7 HTCs

4 Payers



Participant Quotes

“When we have open lines of communication with the payer, we’re able to explain the rationale for therapy decisions and prevent delays that can lead to adverse outcomes. But without that, we’re stuck going in circles through authorization requests and appeals.”

- HTC Provider

“Many people are helping care for this patient... the piece that doesn’t get captured, and probably what some payers are missing, is all of that additional time that the HTC care team is putting in to prevent a hospitalization or bleed.”

- Regional Payer Pharmacy Director



Regional Characteristics

- In the South, HTCs vary in structure, with some offering lifespan programs and 340B services while others lack these resources
- Access challenges include limited HTC availability in certain areas, creating gaps for patients needing specialized care
- Payer-provider communication is inconsistent, leading to difficulties in aligning coverage policies with clinical practice
- Prior authorization is a major pain point, described as an automatic rejection with duplicate authorization forms being required before approval, including renewals
- Network exclusivity limits patients and HTCs choice of specialty pharmacy



Current Challenges

- Some centers operate robust 340B programs, others have programs stalled in administration, and some have no access at all, creating uneven financial and clinical support for patients
- Clinicians reported automatic coverage rejections, duplicate paperwork, and extensive time spent on approvals creating delays in therapy despite requests being clinically appropriate
- Concerns were raised about PBMs controlling both prior authorization and specialty pharmacy services, creating conflicts of interest and inefficiencies in dispensing
- Reliance on telehealth for patients far from treatment centers was highlighted, with concerns about reduced access if temporary flexibilities expire
- Health plans described difficulty engaging members in care management because patients often rely exclusively on treatment centers, limiting payer insight into needs



Opportunities for Collaboration

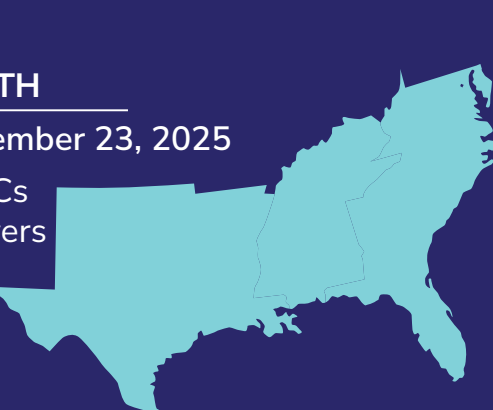
- Encouraging earlier and more direct exchanges to reduce duplicative paperwork, prevent delays in therapy, and align on patient needs
- Collaborating on simplified or standardized PA requirements, especially for established patients, to reduce administrative burden and speed up access to treatment
- Working together to ensure appropriate dispensing and avoid unnecessary shipments, while addressing concerns tied to PBM and specialty pharmacy integration
- Partnering to preserve reimbursement and policy support for telehealth visits, particularly for patients living far from treatment centers
- Creating opportunities for payers to better understand HTC models of care and for providers to learn about benefit design constraints, fostering mutual trust

SOUTH

September 23, 2025

5 HTCs

4 Payers



Participant Quotes

“We’ve actually had a couple of payers reach out to us when there is a question on the PA... they’re reaching out directly to our nurses, which is nice because then you don’t spend the time just spinning around trying to get the PA approved.”

- HTC Provider

“Finding better ways to connect with members and understand their unmet needs beyond what’s addressed at the treatment center would make care management more relevant.”

- Regional Payer Pharmacy Director

Alignment Across Regions



Shared Challenges



Misalignment between payer coverage policies and clinical guidelines



Burdensome prior authorization and fail-first protocols



Limited direct communication between payers and HTCs



Lack of accessible data to support shared decision-making



Shared Opportunities



Expand payer education on clinical innovations and product categories



Foster bidirectional data exchange to demonstrate outcomes and inform policy



Strengthen coordination between payer care managers and HTC clinical teams

Key Takeaways



- **Strengthen internal connections** – Both payers and providers recognized the need to identify who in their organizations is responsible for communicating with the other side, and to ensure those channels are active and effective.
- **Humanize payer perspectives** – Providers valued hearing payer challenges directly, which shifted perceptions by seeing payers as barriers to understanding them as partners working through their own constraints.
- **Proactive outreach over crisis management** – Instead of only reacting to problems, providers emphasized the importance of reaching out to payers early, offering information, and building relationships that can prevent delays in patient care.
- **Amplify the HTC voice** – Continued advocacy and consistent storytelling were seen as critical to ensure HTCs remain visible and influential in payer decision-making.