Comprehensive Care Sustainability Collaborative
National **Bleeding Disorders** Foundation

Stakeholder Perspectives on Sustaining Comprehensive Bleeding Disorders Care: Results from a National Survey and Multi-Stakeholder Roundtables

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BACKGROUND

Hemophilia Treatment Centers (HTCs) deliver integrated, team-based comprehensive care that reduces morbidity and mortality in persons with bleeding disorders. However, the sustainability of this model faces escalating challenges, including fragmented benefit structures, cost containment pressures in self-funded employer plans, PBM-driven access restrictions, and limited payer awareness of the full scope of HTC services — including unbilled care coordination, social work, and physical therapy. The CCSC, a program of the NBDF, convenes payers, employers, brokers, and HTCs to identify collaborative solutions that improve access, care coordination, and outcomes while addressing cost sustainability.

AIMS

To identify the highest-priority threats to comprehensive bleeding disorders care, characterize key access barriers, and define actionable collaborative strategies through multi-stakeholder engagement.

METHODS

A national stakeholder survey (N=23) was conducted in February 2026 among CCSC advisors representing HTCs, payers, and employers. Respondents ranked priority issues facing comprehensive care and identified preferred deliverables.

Two virtual roundtables were held in May/June 2026



Employer/Broker
5 Employers/Brokers
6 HTCs
1 Hemophilia Alliance



East Coast Payer
3 Payers
4 HTCs
1 NBDF

Roundtable participants completed pre-meeting surveys ranking 7 pre-defined access barriers and proposed collaborative strategies, followed by live polling during sessions to identify the most important barrier and the most effective collaborative strategy.

CONCLUSION

Multi-stakeholder engagement through the CCSC identifies convergent priorities for sustaining comprehensive care for bleeding disorders. Across employer, payer, and provider stakeholders, routine data sharing using standardized metrics and outcomes-based contracting were the most promising collaborative strategies. The finding that a lack of awareness of HTC capabilities rivals structural barriers, such as insurance network restrictions and underscores the need for systematic value demonstration. These results support the development of standardized outcomes-reporting frameworks — leveraging infrastructure such as the ATHN registry — to bridge the gap between HTC clinical value and payer/purchaser decision-making.

Stakeholder Perspectives from a National Survey February 2026

National survey respondents ranked **comprehensive care reimbursement sustainability** as the highest-priority issue, followed by **coverage criteria and prior authorization alignment, patient access and continuity of care, and data transparency and outcomes measurement**. The most valued deliverables were practical guidance/frameworks for payer-provider collaboration, policy recommendations, and consensus statements.

Q: Which issues should CCSC prioritize this year? *(Please rank in order from highest priority to lowest priority) Scale 1 = Highest importance and 9 = Lowest importance N=23*

	Average Rank of Importance
Comprehensive care reimbursement sustainability	**2.8**
Coverage criteria and prior authorization alignment	**3.7**
Patient access and continuity care	**4.3**
Data transparency and outcomes measurement	4.5
Site-of-care policies	5.0
Alternative funding models, copay maximizers, and accumulators	5.0
Employer engagement	5.4
Policy or regulatory considerations	5.6
Other: “Brokers/consultants” with employer engagement	8.8

Stakeholder Perspectives Pre-Multi-Stakeholder Roundtables May/June 2026

In pre-surveys, roundtable participants ranked **fragmentation between the medical and pharmacy benefits, PBM control of prior authorization,** and **cost containment pressures** as top access barriers.

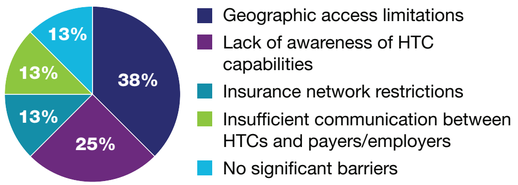
Rank these access barriers to the integrated and comprehensive care model delivered by HTCs. *Scale 1 = Highest importance and 7 = Lowest importance N=14*

Average Rank of Importance	
3.4	**Fragmentation between medical and pharmacy benefits resulting in misaligned coverage and access barriers**
3.4	**PBM control of prior authorization and specialty pharmacy services, contributing to potential access restrictions and conflicts of interest**
3.5	**Cost containment pressures (e.g., high-cost claims in self-funded employer plans) that may restrict access to HTC-based care**
3.7	Limited payer/purchaser awareness of HTC services, including unbilled comprehensive care, leading to undervaluation of the model
3.9	Step therapy and fail-first policies that delay access to appropriate therapy and increase the risk of bleeding events
4.1	Limited communication channels between HTCs and payers/purchasers, hindering coordinated care
5.9	Limited availability of HTCs in rural or underserved areas, reducing access to specialized care

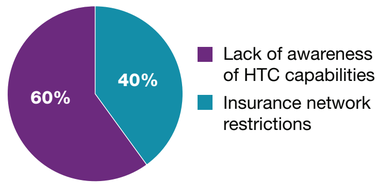
Stakeholder Perspectives from Multi-Stakeholder Roundtables May/June 2026

Q: What is the **primary barrier** to utilizing HTC comprehensive care in your setting? (Select one)

The East roundtable identified geographic access limitations (n=3 of 8) and lack of awareness of HTC capabilities (n=2 of 8) as leading barriers, with insurance network restrictions and insufficient HTC payer communication also identified.

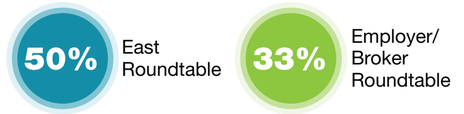


The primary employer/broker barrier was split between lack of awareness of HTC capabilities (n=6 of 10) and insurance network restrictions (n=4 of 10).



Q: Which **collaborative strategy** would most effectively improve the quality and cost-effectiveness of hemophilia care? (Select one)

Routine data sharing between HTCs and payers using standardized metrics was the **top choice** across both roundtables.



Outcomes-based contracting and risk-sharing agreements was the **second-most-endorsed** strategy.



Integrated care coordination with shared accountability and joint development of clinical pathways were also identified as effective collaborative strategies.

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AFM = Alternative Funding Models; **CCSC** = Comprehensive Care Sustainability Collaborative; **PBM** = Pharmacy Benefit Manager; **NBDF** = National Bleeding Disorders Foundation.

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