

CCSC HTC FOCUS GROUP AND SURVEY

Executive Summary - 2023



Comprehensive Care Sustainability Collaborative

National **Bleeding Disorders** Foundation

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Background

The Comprehensive Care Sustainability Collaborative (CCSC) was established in 2014 with two inaugural consensus meetings among health care stakeholders. The aim of CCSC is to provide payers with knowledge crucial for managing the high costs associated with hemophilia and to augment the sustainability of hemophilia treatment centers (HTCs) as centers of excellence by:

- overcoming communication gaps to increase connectivity between payers and providers; and
- disseminating standards of care, quality, and cost management for hemophilia that will provide clarity regarding the value of the HTC integrated care model.

Included in this executive summary are key themes identified during an HTC focus group held at the National Bleeding Disorders Foundation's (NBDF) 75th Annual Bleeding Disorders Conference (BDC) held in August 2023. Also included are results of a survey fielded to HTCs ahead of and in preparation for the HTC focus group.

Executive Summary Prepared by Impact Education, LLC

CCSC HTC Focus Group and Survey Results

CONTENTS

- 2 Background
- 3 By the Numbers
- 3 Key Themes
- 5 Additional Survey Results
- 7 Appendix

Focus Group Goals

- Review what CCSC is and how it can help HTCs address barriers to access
- Share examples of successful HTC and CCSC collaborations
- Learn about:
 - Access barriers
 - Current payer relations
 - Opportunities to collaborate with CCSC

CCSC HTC Focus Group and Survey By the Numbers

August 18, 2023

Date focus group was held

1st

HTC focus group as part of the CCSC program

12

HTC key opinion leaders

24

responses to HTC survey

~78%

percent of survey respondents who indicated their HTCs treat across the lifespan

Key Themes: HTC Focus Group and Related Survey Results

The following key themes were identified from the 90-minute HTC focus group held August 18, 2023.

- **HTC personnel are not as aware of the specific CCSC offerings as they would like to be and would like to learn more.**

It was noted during the focus group that HTC personnel would like to learn more about how CCSC can help them with their work and navigating payer-related issues. They noted that they are often troubleshooting and navigating difficult situations on behalf of their patients but feel that guidance from CCSC could help increase their confidence in this process. Specifically:

- Participants wondered if other HTCs had encountered similar issues at their centers and felt CCSC could be the venue to collect these stories and key learnings so that they may be shared throughout the HTC network.
 - As part of the HTC survey, 72.22% of respondents noted that they have “minimal knowledge” regarding CCSC’s ability to assist HTCs with improving access to high-quality care for patients with bleeding disorders.
 - Additionally, 94.44% indicated they had not received support or assistance from CCSC.
- There was a request by focus group participants to include communication that outlines how HTC personnel can find support through CCSC.
 - The group noted that as an immediate next step, they would like an HTC-specific fact sheet

explaining what the collaborative is and what it can offer HTC personnel specifically. Focus group participants also offered to include the fact sheet or portions of it in their HTC newsletters and other internal employee communications.

- The group also noted that they were unclear when they should contact CCSC vs. the Hemophilia Alliance.
- The findings from the focus group on this topic are in line with the HTC survey responses:
 - Most respondents noted that they hadn't engaged with CCSC, while only one respondent noted that they had "previously received support or assistance."
 - Two comments from the survey are in line with the desire to know more about CCSC and how it can help HTC personnel:
 - One survey respondent noted that they would like additional "communication about the program and how it can support in a direct patient care condition."
 - Another survey respondent noted that they would like additional "visibility" about CCSC given its value.
- The two primary topics identified through the survey that HTCs thought would be important to address as part of CCSC include:
 - "Addressing detrimental out-of-pocket costs caused by alternative funding models, copay accumulator, and/or copay maximizer programs."
 - "Educating purchasers of health care on the overall care and comprehensive services received from HTCs (including evolving novel treatments) and the value they add to optimal patient outcomes."
 - Relatedly, during the focus group, it was noted that HTCs would like coaching on how to navigate and communicate with payers on carve-outs and fail-first approaches. At least two focus group participants noted that it was difficult to get approval for some treatments, and specifically, emicizumab-kxwh.
- Survey respondents also noted that they would like the following as part of the collaborative:
 - "More clearly articulate how CCSC can support HTCs."
 - Additional training and educational sessions; specifically:
 - "More information for those who may have exposure to these issues but are not at the front line."
 - "Offer additional educational programs throughout the years at various community events and conferences."
 - Create a way to submit questions and requests to CCSC to see if the collaborative can assist.
 - Encouragement around patients using "340B pharmacies as opposed to 'mom and pop' specialty pharmacies."
 - A second respondent echoed this statement, noting they would like "more support in serving patients through HTCs pharmacies."
- **HTCs struggle with navigating timely payer approvals to help patients with bleeding disorders facing mental health and/or substance abuse challenges.**
 - Focus group participants shared stories of patients in need of timely, and sometimes critically urgent, mental health and substance abuse care but described the complicated process these patients faced due to logistical hurdles and additional access barriers. It was noted that most mental health and substance abuse treatment facilities would not admit patients who require intravenous (IV) infusions during their stays.

- HTC noted that they have been learning from Chapter organizations, and organizations such as Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) in New England. BD SUMHAC is a coalition of member organizations, including the NBDF. BD SUMHAC's mission is to “advocate for access to appropriate substance use disorder and mental health treatment facilities for all individuals with BD with a focus on inpatient and residential facilities.” While it is not a mental health or substance abuse disorder treatment organization, it helps providers access those services for people living with bleeding disorders. Additional information about this organization can be found here: <https://www.bdsumhac.org/>
- **Issues related to inpatient care.**

Throughout the focus group, participants noted the difficulties they experienced caring for patients living with bleeding disorders when they required inpatient care. Specific examples included:

 - Getting approval for inpatient procedures and admittance to skilled nursing facilities.
 - Sometimes this was due to insurance denials and/or logistics related to care.
 - In terms of logistics related to care, one provider noted that leading up to a long awaited inpatient surgical procedure, the patient's required bleeding disorder treatment (coagulation Factor X) was not available through the hospital pharmacy. The hospital did also not want to approve the patient to bring the product from home to use during the procedure.
 - The general high costs of hospitalization were also noted as well as the need for guidelines related to inpatient care for patients living with bleeding disorders.
 - Participants noted the Skilled Nursing Facility (SNF) bill that allows SNF's to provide treatment(s) related to bleeding disorders or contract with a third-party (HTC or specialty pharmacy). It was noted that a resource be created for HTCs outlining what the SNF bill addressed and how to bill for medications as a carve out to Medicare Part A. This resource would be something that HTCs could easily reference.
- **Proactive patient education is needed to help empower patients, so they are aware of alternative funding models and how to respond to unsolicited communications and requests.**

It was noted by focus group participants that when patients are contacted by their insurers or third-party groups working with their insurers, these contacts often identify themselves as “advocates” that are there to help the patient. Focus group participants felt patients should be educated about what kinds of communications (similar to the example shared above) they may receive and how to navigate these conversations. They should also be informed about what is being asked of them as employees, as it was noted that patients often feel unsure of what is being asked of them and what the consequences are of not participating in these programs. Specifically, patients feel they need to take the no- or low-cost treatment vs. the treatment that was prescribed to them by their physician. Similarly, participants felt there is a need for clear educational tools and resources to educate HTC staff on both versions of the alternative funding models. These materials would broadly explain alternative funding models but would also highlight the ways in which providers can communicate with their patients about these topics.

Additional Survey Results At a Glance:

- 24 HTCs responded to the survey and most noted that they provide lifespan treatment and support to the bleeding disorder community.

- Most indicated that they treat bleeding disorders including hemophilia (with and without inhibitors), von Willebrand Disease (VWD), other factor deficiencies, and platelet disorders.
- 27.78% of HTC's responding to the survey said that they have an in-house or parent institution pharmacy. The same percentage said they also indicated that they work with a contract pharmacy.
- 3 HTC survey respondents indicated that their HTC's do not have an in-house or parent institution pharmacy or contract pharmacy.

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Appendix

HTC Focus Group - AGENDA

August 18, 2023
 7:00 – 8:30 am ET
 NHF's Bleeding Disorders Conference (BDC)
 Gaylord National Harbor
 Potomac 3 | Ballroom Level
 National Harbor, MD

6:30 – 7:00 AM	Buffet Breakfast	All
7:00 – 7:15 AM	Welcome Review Meeting Goals Introductions	Kollet Koulianos, MBA
7:15 – 7:35 AM	CCSC Results: Successful Collaborations with HTCs	Becky Burns Jennifer Borrillo, MSW, LCSW, MBA Jeff Blake, MBA
7:35 – 7:45 AM	Question and Answers	All
7:45 – 8:20 AM	Moderated Focus Group Discussion Part I: Discussion of issues the HTCs deal with in their respective communities Part II: Discussion CCSC/HTC issues	Kollet Koulianos, MBA
8:20 – 8:30 AM	Review of Key Takeaways and Next Steps	Kollet Koulianos, MBA