

MULTI-STAKEHOLDER MEETING

Executive Summary | December 5, 2023

CONFIDENTIAL

Jointly developed by



VBCDC is supported by charitable donations
from CSL Behring, Sanofi, and Takeda.

Background

The Value-Based Chronic Disease Collaborative (VBCDC) brings together payers and patient advocacy groups (PAGs) to facilitate value-based partnerships that improve:

- ✓ Quality
- ✓ Access
- ✓ Value

for the management of high-cost, chronic diseases. This proactive and collaborative approach allows the development of strategies specifically tailored to the unique characteristics of each patient population.

VBCDC conducts semi-annual virtual meetings attended by representatives from national patient organizations as well as healthcare payers and purchasers.

The success of VBCDC is based on the understanding that data and analytics have the potential to improve methods for controlling high-cost claims. Therefore, it is critical for payers and patient advocates to come together to share insights and identify relevant data that is most beneficial for successful patient outcomes and advocacy.

Value-Based Chronic Disease Collaborative

CONTENTS

- 2 Background
- 3 VBCDC By the Numbers
- 4 Meeting Highlights
- 5 Participating Organizations
- 6 Program Evaluation
- 7 Appendix

2023 STRATEGY

VBCDC is a critical part of the National Bleeding Disorders Foundation (NBDF) efforts to achieve optimal outcomes for patients at the lowest total cost of care.

In 2024, VBCDC will continue to bring together key opinion leaders from the payer, healthcare, and patient advocacy space. The goal of this forum will be to assist with the:

- Focused educational opportunities
- Leverage the value of collaboration between these groups

PROPOSED NEXT STEPS

- Monitor opportunities and provide support that improves processes and communication between payers and patient advocates
- Host additional training webinars in 2024
- Create a web portal for VBCDC resources

VBCDC By the Numbers

3rd

year of VBCDC program, launched in 2020

7th

virtual multidisciplinary stakeholder meeting held since program launched

December 5, 2023

VBCDC meeting

34

experts from payer and PAGs attended

24

organizations (payer and PAG) pre-registered for the meeting

4

new PAGs joined VBCDC for this meeting

Meeting Highlights

Expert faculty presented on timely topics relevant to various therapeutic areas: the group received special presentations on the Inflation Reduction Act (IRA) from Dr. Troyen Brennan, the former Chief Medical Officer of CVS and Aetna. He is currently an adjunct professor at Harvard. Kate Reinhalter Bazinsky, MPH also presented to the group, representing BD SUMHAC, an organization that is addressing access to in-patient mental health care for those living with chronic conditions. BD SUMHAC is a collaborative effort with the NBDF and the Hemophilia Federation of America.

The IRA is complex and requires additional education for all stakeholders: participants noted that education will be key as the IRA rolls out and is implemented. Specifically, how biosimilars will be prescribed and reimbursed should be a topic of education as treatments are not interchangeable for everyone. Participants noted that it will be critical to follow the science on non-medical switching.

“And it was really their [patient advocacy groups] advocacy that very much kept the federal government focused on the IRA and has brought about these changes. They saw that with the Affordable Care Act, and you see that today. So, I think...sort of in some ways, very much thanks to the patient advocacy groups.”

-Troyen Brennan, M.D., M.P.H.

Raising the issues patients have when seeking in-patient care for mental health, substance use and ambulatory care to payers: Kate Reinhalter Bazinsky highlighted major issues patients face when seeking in-patient care for mental health and substance use disorders:

1. Facilities not accepting patients with chronic conditions because they are ill-equipped or are uneducated on the reality of the chronic condition.
2. When admitted to an in-patient facility, treatment for chronic condition is often held.

“...we conducted a national study of all the hemophilia treatment centers nationwide, we found that 83% of providers who attempted to refer a patient with a bleeding disorder to treatment for their mental health needs received a denial. And this was true in a number of states across the country with no obvious geographic pattern or concentration. It is really a national problem.”

- Kate Reinhalter Bazinsky, MPH

Participating Organizations

Patient Advocacy Groups Represented



Payer Participants

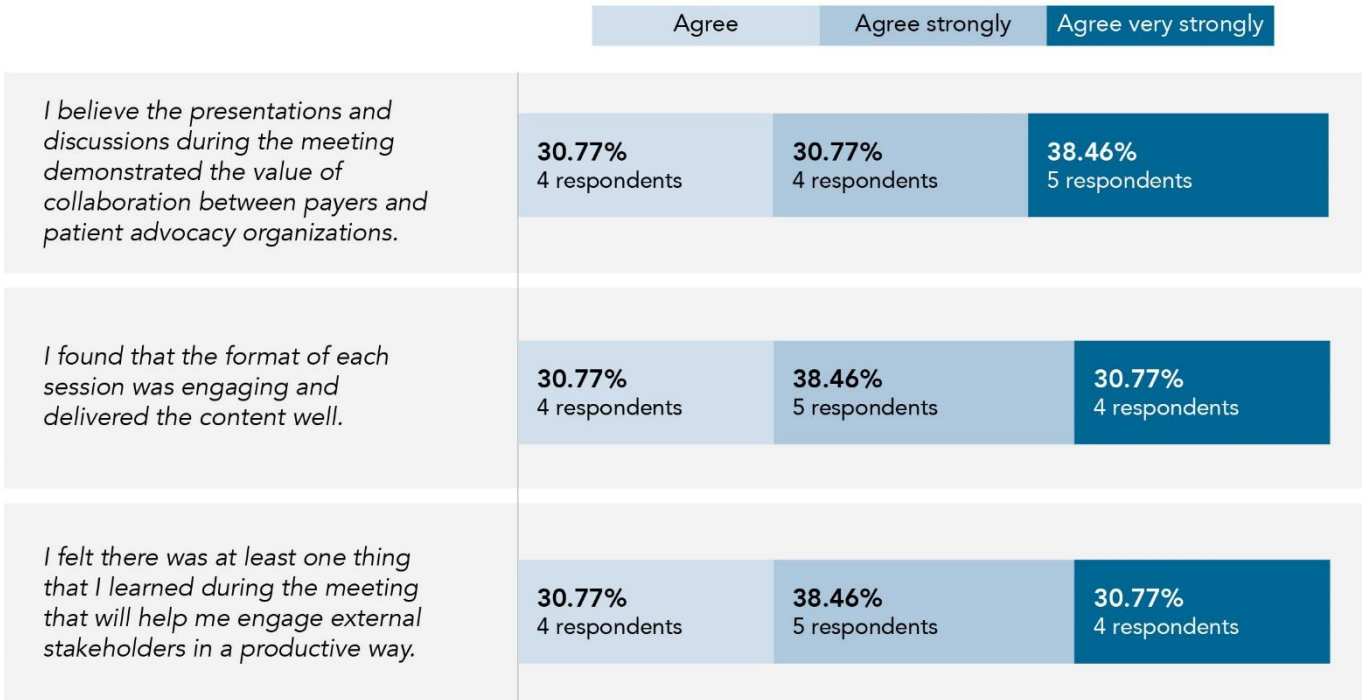
- Cynthia Reilly, MS, BS, Pharm. Consultant
- Melody Bautista, BCS Financial
- Fodayemi Fashola, PharmD, BCACP, MSCS, Kaiser Permanente
- Michael Howcroft, BS, Care Source
- Jeff Dunn, PharmD, MBA, Cooperative Benefits Group/RealRx
- James T. Kenney, RPh, MBA, JTKENNEY, LLC
- Zachary Contreras, PharmD, Sharp

PROGRAM EVALUATION

Following the meeting, a program evaluation was sent to participants asking them to provide feedback on the agenda, sessions, and discussion. **A total of 13 responses were received 6 from payers; 6 from PAGs and 1 from industry.**

100% of participants that responded to the evaluation survey said that they would continue to participate in VBCDC.

Participants were asked to rank on a 6-point Likert scale the extent to which they agreed with the below statements. All respondents (13) rated their level of agreement of at least “agree” with the following percentage breakdown:



Looking Forward

VBCDC Participants would like to additional support in:

- Identifying strategies stakeholders are using and/or planning to use to address the high-cost of gene therapies and other ultra-high-cost treatments in the pipeline.
- PAG and payer discussions that are broadly applicable across various therapeutic areas.
- Understanding the impact of changes to Medicare rules on access to medications for rare diseases.
- Resources on education that is being developed for community advocates and patients on gene therapies.
- Resources and training on avenues and best practices for outreach/communication when contacting a policymaker. Guidance on what information policymakers find helpful/impactful.
- Discussion on the risks of using artificial intelligence (AI) algorithms to facilitate medication denials.
- Education and discussion on congenital adrenal hyperplasia, a group of hereditary (inherited) genetic disorders.

Appendix

Agenda

Today's Agenda



Time (ET)	Topic	Speaker(s)
12:00 PM	Welcome and Opening Comments	James Kenney, RPh, MBA; Edmund Pezalla, MD, MPH -VBCDC Co-Chairs Kollet Koulianos, MBA (National Bleeding Disorders Foundation, NBDF)
12:10 PM	Introductions	Ed Pezalla, MD, MPH
12:20 PM	Inflation Reduction Act: Shared Implications for Payers and Patient Advocacy Groups	Troyen Brennan, MD, MPH Harvard T.H. Chan School of Public Health
12:40 PM	Q&A and Discussion	Troyen Brennan, MD, MPH Ed Pezalla, MD, MPH
1:00 PM	Break	
1:05 PM	Case Study: Bleeding Disorders, Mental Health Treatment and Payer-Related Considerations	Kate Reinhalter Bazinsky, MPH Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) <i>Introduced by Nathan Schaefer, NBDF</i>
2:00 PM	Case Study Reflection: Group Discussion	James Kenney, RPh, MBA
2:45 PM	Recap and Next Steps	Ed Pezalla, MD, MPH Ryan Faden, JD, MPH NBDF