



Connecting Payers and Advocacy Organizations

MULTI-STAKEHOLDER MEETING

Executive Summary | June 8, 2023



VALUE- BASED CHRONIC DISEASE COLLABORATIVE

Connecting Payers and Advocacy Organizations

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 of healthcare.

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.

Value-Based Chronic Disease Collaborative

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2023 STRATEGY

VBCDC is a critical part of the National Hemophilia Foundation's (NHF) efforts to achieve optimal outcomes for patients at the lowest total cost of care.

In 2023, 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:

- implementation of disease programs
- identification of innovative reimbursement strategies
- additional related efforts that 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 2023
- Host next VBCDC stakeholder meeting in Q4 2023
- Create portal for VBCDC resources

Executive Summary Prepared by Impact Education, LLC

Jointly developed by



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VBCDC By the Numbers

June 8, 2023

Date of latest VBCDC meeting held

3rd

year of VBCDC program, launched in 2020

6th

virtual multidisciplinary stakeholder meeting held since program launched

48

experts from payer and patient advocacy organizations attended

29

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

4

new patient advocacy organizations joined VBCDC for this meeting

Program Planning

The agenda for this meeting was developed by a subcommittee, which included:

- Michele Guadalupe, MPH (National Eczema Association)
- Olivia G. Dieni, MPH (Cystic Fibrosis Foundation)
- Mariah Scott, MS, MPH (Sick Cells)
- Peter Harvey, MBA (National Hemophilia Foundation)
- Kollet Koulianos, MBA (P3 Healthcare Benefit Consulting)
- Yahaira Rivera Bobadilla, M.B.Ed. (Multiple Sclerosis Association of America)
- Dana McCormick, RPh (BCBS of Texas)
- Edmund Pezalla, MD, MPH (VBCDC Co-Chairs)
- James Kenney, RPh, MBA (VBCDC Co-Chairs)

Agenda Highlights

Main highlights included:

- Review of pre-work findings:** Registered VBCDC participants were asked to complete a survey (either from their perspective as a payer or patient advocacy group) to determine where their organization is on their payer-patient advocacy group engagement journey. Additionally, the pre-work survey was fielded to Impact Education’s proprietary learner database to query a wider set of payer professionals. Results were discussed as part of group introductions at the start of the meeting. A topline summary of those findings is included later in this report.
- Profiles of Two Health Technology Assessment (HTA) Groups—ICER and IVI:** Didactic presentations from two health technology assessment organizations, The Institute for Clinical and Economic Review (ICER) and The Innovation and Value Initiative (IVI) were led by their patient engagement leads respectively: Catherine (Cat) Koola and Erica deFur Malik. Audience led Q&As followed each of the presentations.
- Perspectives on Engagement with HTAs—Panel Discussion:** A panel discussion moderated by VBCDC co-chair Jim Kenney included patient advocacy group representatives along with ICER and IVI. The panel discussed their organization’s engagement with both groups and how VBCDC patient advocacy groups may get involved in-assessments these organizations conduct and, along with payers, leverage the resulting reports. Panel participants included:
 - Mariah J. Scott, MS, MPH (Sick Cells)
 - Olivia G. Dieni, MPH (Cystic Fibrosis Foundation)
 - Michele Guadalupe, MPH (National Eczema Association)
 - Johanna Gray, MPA (Artemis Policy Group – NHF’s federal policy advisor)
 - Catherine Koola, MPH (ICER)
 - Erica deFur Malik, MTS (IVI)
- A Discussion on Patient Reported Outcomes (PROs):** The VBCDC subcommittee noted it was a priority to hear more about how patient advocacy groups can utilize patient reported outcomes as part of their payer strategy. A fireside chat format was used so participants could hear directly from Mariah J. Scott (Sick Cells) given her organization’s ongoing use of patient reported outcomes. During the session, led by Ed Pezalla (co-chair, VBCDC), audience questions were taken and incorporated into the discussion.



Title slide: Cat Koola’s Presentation during VBCDC meeting



Title slide: Erica deFur Malik’s Presentation during VBCDC meeting

Please note: the full agenda is included in the Appendix of this document.

Pework Findings

A survey was fielded prior to the meeting to the payers and patient groups in attendance. The survey was also fielded to Impact Education, LLC's proprietary learner database of payer professionals, which includes about 14,000 qualified managed care and payer professionals. The VBCDC pre-work survey found that PAGs and payers engage at various levels with PAGs reporting a more proactive outreach approach. A breakdown of responses and findings from the survey are highlighted below:

13

PAG survey responses

62% indicated that their organization currently proactively reaches out to payers

31% would like to reach out to payers, but they do not know how to identify appropriate contacts

8% noted they were not currently engaging with payers

87

Payer survey responses

23% report reaching out to PAGs on specific issues

14% also said they proactively reached out to PAGs about treatments in development or the community they serve

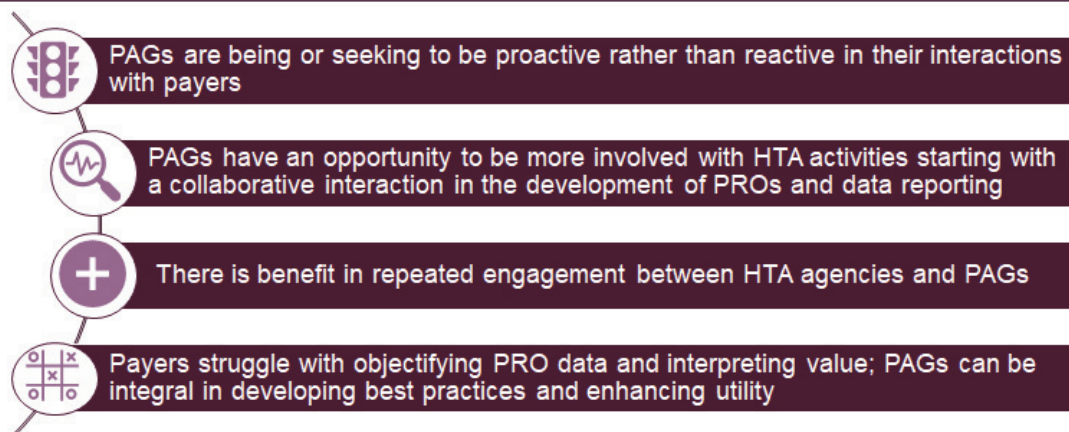
12% reported they are not engaging with PAGs at all

11% would like to reach out to PAGs, but do not know who to reach out to

Key Takeaways

At the conclusion of the meeting, key takeaways from the group discussion were shared. An overview is below, with additional highlights for each included.

Key Takeaways from June 8, 2023 VBCDC Meeting:



PAGs are being or seeking to be proactive rather than reactive in their interactions with payers

Patient advocacy group representatives were asked to give a “thumbs up” or “thumbs down” on whether they felt their group was proactively reaching out to payers to engage. None of the advocacy groups gave themselves an outright “thumbs down”. While one noted “a big thumbs up” others felt they were earlier on the path towards being engaged with payers, especially proactively. One national patient organization’s insight into what topics they’ve been engaging around: “we have been very vocal on issues such as step therapy and prior authorizations.”

PAGs have an opportunity to be more involved with the HTA activities starting with a collaborative in the development of PROs and data reporting

The power of PROs in the HTA process were discussed, with PAGs having an integral role in championing this process. Ed Pezalla, MD, MPH reminded the group that “PROs are measures of...the patient’s health status...directly reported by the patient...it’s not someone else’s interpretation.” Overall, PAGs and payers acknowledged the power patients have not just by participating in PRO opportunities. As IVI noted in terms of their assessment process: patient engagement is not a one-off activity: “we want to make sure that we are co-authoring, co-partner on our entire process and make sure that...our reports, but also our...thought leadership and engagement activities reflect the values and needs of the entire stakeholder community.” Additionally, ICER outlined all the ways that they engage patients in their assessment process, noting: “patient input is very critical to ICER’s process.”

The earlier PAGs can engage with HTA agencies and/or relevant stakeholders to help refine and focus PROs, the better.

There is a benefit in repeated engagement between HTA agencies and PAGs

Across the board – from presentations from ICER and IVI as well as VBCDC participants– it was noted that engagement between HTAs and PAGs is really at its best when both parties are able to work with each other overtime. For example, faculty member Joanna Gray, MPA highlighted that after a series of hemophilia related health technology assessments with ICER, NHF has identified the “right types of stories” and the “right providers” to engage. Meanwhile, ICER has “gotten a lot smarter about hemophilia” and informed about the space, and as a result, has produced informed analyses.

Payers struggle with utilizing PRO data and interpreting value: PAGs can be integral in developing best practices and enhancing utility

Mariah J. Scott, MS, MPH (Sick Cells) and Ed Pezalla, MD, MPH participated in a fireside chat style session on PROs. Mariah noted that one thing PAGs can do is fill in the blanks for payers with PROs, noting: claims are just “a snapshot, [a] cross sectional snapshot” but without data to reflect what happened leading up to and following the hospitalization, payers are limited to the claims data reflective of that one point in time.

Payers acknowledged the importance of PROs, but also struggled with how PRO data can be utilized and integrated into their work when the data itself is subjective. One payer noted, “I’m struggling with...how do we as payers understand...what is meaningful, what can be captured? How do we objectify such a subjective process...?” It was further noted that the process overall, both from PAGs and the payers’ use of the PRO data should be revisited to determine:

- How the PRO process can be done in a seamless, mutually beneficial way that doesn’t cause participant fatigue
- Specific things to measure so that at the end of the process, the data collected fits “into the story of value...in a meaningful way...” and is collected in a prospectively.
- The expectations of the data collection – so that PAGs and payers aren’t answering everything “under the sun” and for the questions that are prioritized, rich data and insights are available to both parties vs. partial data on various topics.

VBCDC Faculty Highlights

Didactic Presentations and Q&A with HTA Leaders:



Caterine Koola, Associate Director Patient Engagement



Erica deFur Malik, Director of Patient Engagement

Panel Discussion from:



Patient Reported Outcomes Discussion:



Ed Pezalla, MD, MPH



Mariah J. Scott, MS, MPH

Participating Organizations

Patient Advocacy Participants



New Patient Advocacy Participants



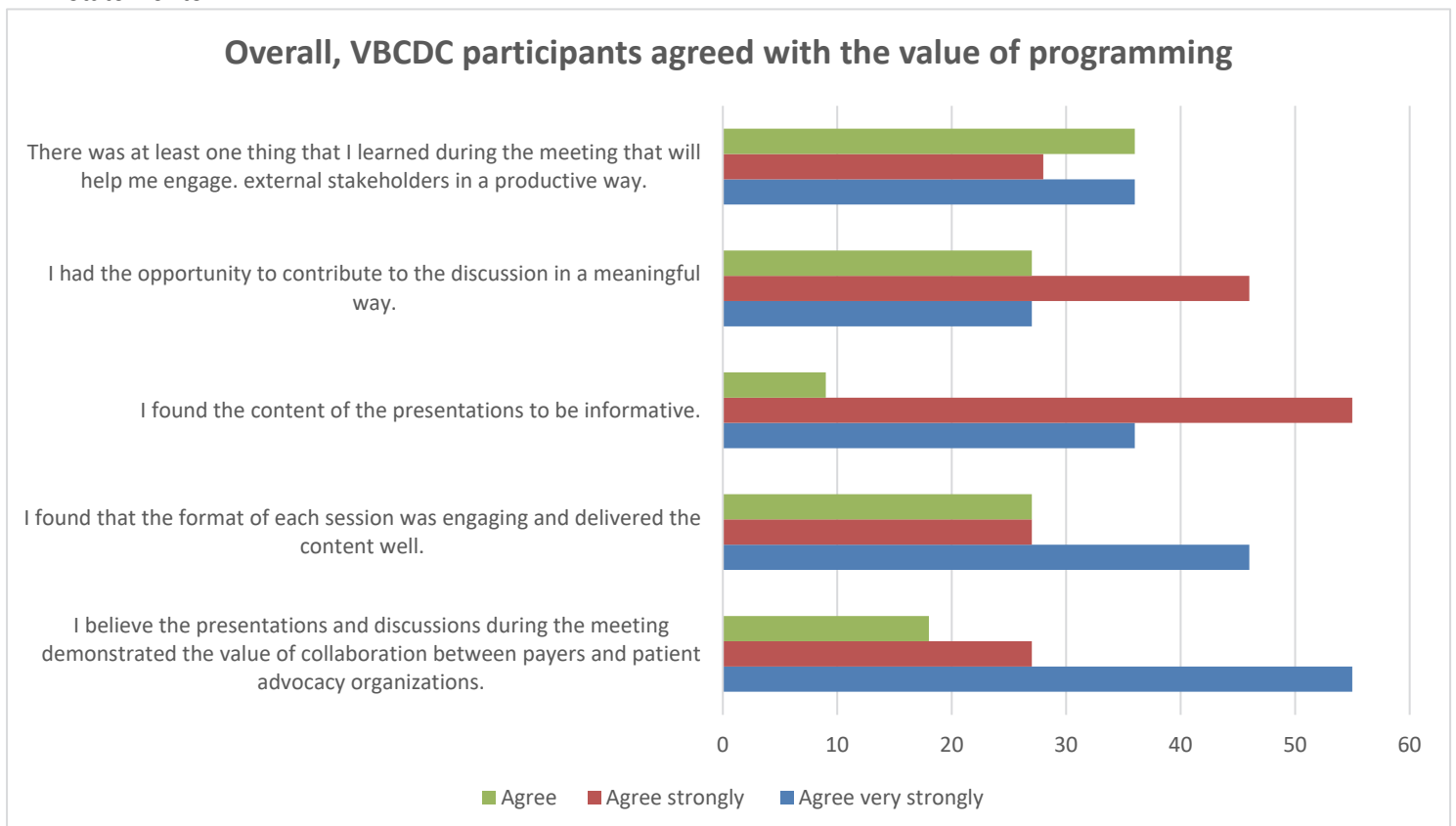
Payer Participants

AscellaHealth	JTKenney, LLC
BCS Financial Corp.	(Former Harvard Pilgrim Health Care)
CareSource	MMDLopes, LLC
Cooperative Benefits Group	(Former CMO: Horizon BCBSNJ, EmblemHealth, and MagellanRx)
(Former Haven, MagellanRx, and SelectHealth)	Sharp Health Plan, Health Services
Enlightenment Bioconsult, LLC	
(Former Aetna, Inc.)	

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 11 responses were received (3 from payers; 8 from PAGs). Below please find a topline breakdown of key findings:

Participants were asked to rank on a 6-point Likert scale the extent to which they agreed with the below statements.



Participants were also invited to describe future topics they would like to see addressed as part of the next VBCDC meeting agenda. Overall, the group expressed interest in:

- How PROs can be applied to payer decision making and,
- Case studies that showcase practical tips – both from a payer and patient advocacy group perspective

Below please find a full list of suggested topics:

- *How we can, as a community - and including ICER, work together to evolve measurement tools for HTA so they are more inclusive of real world evidence. There's some efforts from patient groups (not ours) to ban use of the QALY with no back up recommendations for substitution. Without a substitution, bans are highly unlikely - although the efforts shine an important light on the issues.*
- *I would like to continue the discussion on how to incorporate PRO. For example, how is it measured or could be incorporated into an already existing "scoring" system for P&T committee.*
- *Learn from patient advocacy organizations and payers of their collaborations and what has worked, what the challenges were, potential solutions, & their recommendations.*
- *Perhaps a case study or practical tips surrounding a situation like this: We try to get to know payers before any issues happen, but inevitably an issue comes up from a payer that we haven't met with. What is the best way to work with that payer, especially given that we don't get a lot of notice that a formulary change (or other issue) is about to happen - and in many cases we don't have a good contact at that particular company*
- *Model outreach and engagements between the payers and patient groups. How to locate whom to talk to. What do payers value most about patient group communications? If early engagement (before problems arise) is preferred, what does that look like? An intro call to introduce your patient group and barriers to care and impacts of delayed treatment? patient stories? How can groups work together to raise awareness among clinicians on properly coding something for reimbursement? Often times we hear stories of denials and treatment delays that could have been avoided if coded properly.*
- *I'd like to hear how payers use clinical trial/Real World Evidence in determining coverage of therapies.*
- *VBC best practices including ex US*

###

Appendix

Agenda

Thursday, June 8, 2023

12:00 pm – 4:00 pm ET

12:00 PM	Welcome and Opening Comments	James Kenney, RPh, MBA (JTKENNEY, LLC) VBCDC Co-Chair Peter Harvey, MBA National Hemophilia Foundation
12:10 PM	Introductions and Review Pre-Work: Where Advocacy Groups and Payers are In Terms of Engagement	Ed Pezalla, MD, MPH (Enlightenment Bioconsult LLC) VBCDC Co-Chair
12:40 PM	Profiles of Two HTA Groups: ICER and IVI	Catherine Koola, MPH (ICER) Erica deFur Malik, MTS (IVI)
1:30 PM	Perspectives on Engagement with HTAs: Panel Discussion	<ul style="list-style-type: none"> • Catherine Koola, MPH (ICER) • Erica deFur Malik, MTS (IVI) • Mariah Scott, MS, MPH (Sick Cells) • Olivia G. Dieni, MPH (Cystic Fibrosis Foundation) • Michele Guadalupe, MPH (National Eczema Association) • Johanna Gray, MPA (Artemis Policy Group; NHF federal policy advisor) <p style="text-align: right;">James Kenney, RPh, MBA (Moderator)</p>
2:15 PM	Break	
2:25 PM	A Discussion on Patient Reported Outcomes (PROs)	Ed Pezalla, MD, MPH and Mariah Scott, MS, MPH
3:00 PM	Revisit Pre-Work: Group Discussions Regarding Patient Reported Outcomes	James Kenney, RPh, MBA
3:45 PM	Recap and Next Steps/Adjourn	Ed Pezalla, MD, MPH Peter Harvey, MBA