



## MULTI-STAKEHOLDER MEETING



Executive Summary | January 27, 2023

**CONFIDENTIAL**



Connecting Payers and Advocacy Organizations

The Value-Based Chronic Disease Collaborative (VBCDC) brings together payers, providers, and patient advocacy organizations to facilitate value-based partnerships that improve quality, access, and 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 purchaser organizations.

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

Prepared by Impact Education, LLC

## Value-Based Chronic Disease Collaborative

### CONTENTS

- 1 How Payers Assess the Cost Effectiveness of Treatments: A Primer on Health Technology Assessment (HTA)
- 2 Update on Alternative Funding Models
- 3 Equity and Affordability: Sickle Cell Disease Case Study and Workgroup Session
- 4 Participants

### 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 additional 2023 VBCDC stakeholder meetings
- Create portal for VBCDC resources

## Background

On January 27, 2023, VBCDC convened their semi-annual virtual multidisciplinary stakeholder meeting, with 45 experts from payer and patient advocacy organizations.

Accountable Health, LLC, Sick Cells, Blue Cross Blue Shield of Texas, Highmark, and members of the VBCDC steering committee led didactic and case study presentations, which were combined by a series of group discussions.

## How Payers Assess the Cost Effectiveness of Treatments: A Primer on Health Technology Assessment (HTA)

### Key Findings

- HTAs will be increasingly important for stakeholder groups, especially payers, manufacturers, patient advocacy groups, and patients as HTA findings are being considered in P&T committee formulary decision making processes.
- Parameters around what is measured and how it is measured as part of HTAs is evolving to include contextual considerations and other potential benefits, which is viewed as valuable, as the more data included as part of an HTA, the better positioned payers are to make informed coverage decisions.
- The HTA process and methodology must be transparent.
- Patient advocacy groups play an important role in ensuring that patients realize their opportunity to contribute to patient registries and ultimately influence the data incorporated into HTAs.

### 1.1 Current Challenges

HTAs present an opportunity for stakeholders, including patient advocacy groups, payers, manufacturers and HTA agencies to work together to identify opportunities to collect and review meaningful data; however, this process presents some challenges. Among the most prominent identified by participants were:

**Agreeing on what “value” means across stakeholders remains a challenge.** Understanding value across multiple perspectives would create trust in value-based approaches and increase stakeholder alignment. Establishing a common language on value in healthcare would facilitate connections across the value-focused reforms (e.g., HTA, value-based contracting, value-based care models) being implemented.

**HTAs are tools that help payers make evidence-based formulary decisions.** P&T committees may utilize an HTA to determine whether a product (technology) will require prior authorization or step therapy, and to negotiate contract pricing.

**In the US, HTAs are non-binding and primarily used to supplement coverage policies and negotiate pricing.** The Institute for Clinical and Economic Review (ICER) is gaining national prominence for their use of systematic reviews of clinical effectiveness and incorporation of feedback from patients, clinicians, manufacturers, and payers to frame the scope of their HTAs.

**Health technology assessment (HTA):** the systematic evaluation of properties, effects, and/or impacts of healthcare technology. It may address the direct, intended consequences of technologies as well as their indirect, unintended consequences. Its main purpose is to inform technology-related policymaking in healthcare. HTA is conducted by interdisciplinary groups using explicit analytical frameworks drawing from a variety of methods.

### ***1.2 Opportunities for Collaboration***

Data collection was identified as a major collaborative opportunity. Participants identified two ways patient advocacy groups could foster collaboration:

**Be data driven.** Participating payers encouraged advocacy groups to discuss opportunities to collaborate and share patient-reported data. Specifically, patient-centered data demonstrates the disease impact can meaningfully contribute to HTAs. While anecdotal stories and case reports can be compelling to payers, quantifying and presenting them in aggregate will provide a more valuable picture of the patient experience to a payer audience.

**Encourage patients to participate in data collection initiatives.** Patient groups can engage and educate individuals on the importance of participating in data collection initiatives (e.g., registries, surveys, etc.) If patient communities have a Centers of Excellence network, patient groups can collaborate with these Centers to collect and share aggregate data. Advocacy organizations are well positioned to facilitate real-world data collection, which allows stakeholders to discover aspects of new therapies and devices that may not have been identified in the controlled clinical trial setting.

## Update on Alternative Funding Models

### Key Findings

- Approximately 40% of employers have either implemented or are considering implementing alternative funding solutions.
- These models can be highly disruptive to impacted members and as a result may have a determinantal impact on patients and overall healthcare spend and possible compliance risks for health plans.

The increasing cost of healthcare is a great concern for many stakeholders, including employers. Specialty drugs are often targeted for cost mitigation techniques because of their higher cost but lower utilization. However, specialty drugs are often the only treatment that can be used for certain conditions—and frequently there are no lower-cost alternatives available. Alternative Funding Models may be an attractive measure for self-funded employers, but present challenges and have unintended consequences for patients and employees.

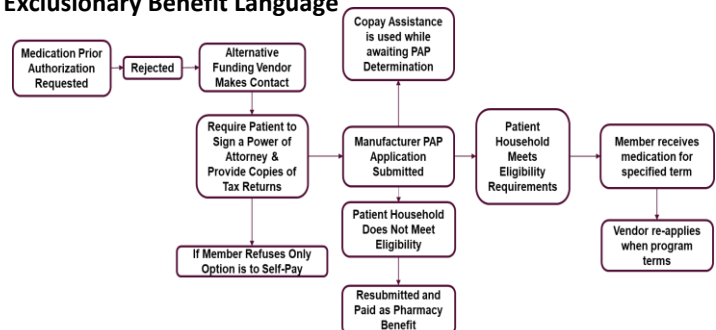
Kollet Koulianos, MBA, (NHF) presented and led a discussion of two ways Alternative Funding Models are being implemented:

1) *Approach 1:* The health plan will carve out all or some drugs to treat a condition from the plan benefits and notify members who then are referred to a third-party alternative funding vendor. Under this approach, specialty drugs are not considered an essential health benefit, even though prescription drugs are. The patient in essence is uninsured for the carved-out drugs and receives a denial letter for the prescription.

2) *Approach 2:* Rather than exclude drugs from coverage, use the prior authorization process to send prescriptions to the Alternative Funding Vendor. The affected medications may appear covered under the formulary with prior authorization, and patients are often surprised by coverage denials and can unexpectedly be left without access to treatments. Delays in access to medically necessary medications could lead to gaps in treatment, disease progression, or use of emergency care, which ultimately drives up the total cost of care.

**Alternative Funding Models** describes “solutions” targeted to employer self-funded health plans to help those plans reduce their specialty drug spend and catastrophic claims exposure by partially or fully excluding coverage of specialty medications from their prescription drug benefit and requiring patients to use manufacturers’ patient assistance programs (PAPs) to gain access to their prescribed therapies.

**An Alternative Funding Model Flow Chart That Avoids Exclusionary Benefit Language**



In both models, if a patient does not qualify for the manufacturer PAP, the plan covers the specialty drug via an exception process.

### **2.1 Current Stakeholder Concerns**

**Rising healthcare costs and drug spend:** Addressing rising healthcare costs and drug spend has been a focus of healthcare stakeholders for many years. Employers are constantly evolving their strategies to provide affordable health insurance. Approximately 40% of employers surveyed (n=97) in 2022 by Gallagher Research & Insights reported they have either implemented or are planning to use Alternative Funding Models in the next five (5) years. The impact of these programs on healthcare costs and patients is just starting to be realized. Major concerns include that the projected cost savings will not be as significant as marketed, that the disruption to coverage and treatment will ultimately cost plans more time and money, and the impact on patients will be highly disruptive.

**Potential for ERISA- or IRS-related compliance issues:** Internal Revenue Code Section 105(h) contains nondiscrimination rules for self-insured health plans. Under these rules, self-insured plans cannot discriminate between higher and lower wages for individuals with respect to eligibility or benefits. Since these models rely on manufacturer-sponsored PAPs, eligibility for free drug or financial assistance is based on income, which may conflict with ERISA and IRS rules.

**Significant risks to patients:** Alternative Funding Models exploit the intent of PAPs, which is to help patients who cannot afford the cost of a medication. Growing use of these models could cause manufacturers to change or limit the availability of PAPs, taking away an important means of treatment for patients. Additional risks to patients may include:

- Lack of continuity of care, delayed care, or adherence issues—and their related impact on clinical outcomes
- Increased financial and administrative burden
- Privacy concerns around sending personal health information to third parties

### **2.2 Opportunity for Collaboration**

**Identify and communicate the clinical consequences of these programs.** If the condition isn't properly managed because access is disrupted, the clinical consequences may be profound. From a payer and employer perspective, this may greatly increase costs. There is an opportunity to collaborate and educate how these models impact patients, employees, and cost. Advocacy groups are uniquely positioned to illustrate the unintended consequences of these models through real-world case studies. Payers noted it is important to quantify the impact by detailing the increase in the total cost of care. Employers and payers need to be aware of the potential compliance risks as it relates to rules for self-insured health plans.



## Equity and Affordability: Sickle Cell Disease Case Study

### Key Findings

- Utilization management strategies have an impact on the SCD community.
- The SCD community needs are not being met in terms of access to adequate care.
- Patient advocacy organizations are working to understand and address access barriers. Sick Cells, in particular, is addressing this through an equity lens.

People living with and those caring for someone with SCD struggle to navigate the healthcare system for a variety of reasons. As more novel, high-cost therapies (i.e., gene therapy) are developed, there is increased concern around access.

### 3.1 Current Experience and Challenges

La'Shardae Scott, mother of two Sickle Cell Warriors and a Sick Cells Ambassador, shared her perspectives on the realities the SCD community faces.

**Sickle Cell Disease (SCD)** describes a group of inherited red blood cell disorders. In SCD, hemoglobin is abnormal, which causes red blood cells to resemble a C-shaped tool called a "sickle." Vaso-occlusive events (VOEs) are the hallmark of SCD.

#### Patients and families struggle to navigate the healthcare system.

Patients and families spend significant amounts of time navigating prior authorization and insurance appeals. Some report having to choose between paying for their treatment and daily living expenses. Ancillary care costs (e.g., supplies) are generally not considered when discussing treatment affordability but can be a considerable expense for patients with SCD.

**Maintaining full-time employment is difficult due to the unpredictability of SCD.** Vaso-occlusive events (VOEs) can occur without warning and can have an abrupt and severe impact on patients' quality of life. Vaso-occlusive pain crisis is the most common and the leading cause of hospitalization. Because of these recurrent syndromes, patients and their caregivers often have difficulty finding and keeping a job. Both patients and their families report significant financial hardship because of SCD. In addition to lost wages, there are significant out-of-pocket costs due to the disease.

#### Utilization management impacts the SCD community by limiting access to life-sustaining treatments.

Treatment of SCD requires a long-term, comprehensive approach to improve outcomes and quality of life. There is a need for individualized treatment based on short-term risk of death or progression to permanent disability. Patients express frustration with the lack of proven therapies for SCD relative to other diseases. There is also concern that if new treatments become available, there will be delays in access due in part to provider knowledge and treatment costs. While there is enthusiasm for new therapies, patients want assurance they are safe and effective in the long term.

**Systemic issues impact the care of patients with SCD.** Patients with SCD may be perceived by healthcare providers as drug-seeking, which can result in delays in getting adequate pain medication or life-saving interventions. Racism and bias have negatively affected access to care, treatment, and health outcomes for individuals most affected by SCD.



### 3.2 Opportunities for Collaboration

Sick Cells' data-driven initiatives seek to understand and address access barriers through an equity lens. Sick Cells and Avalere Health outlined how factors such as income and other demographics influence access barriers in the SCD community. In April 2022, Sick Cells published the report, "[Medicaid Access & Landscape Review For Prescription Drugs treating Sickle Cell Disease](#)." This report outlines the programs, carve-outs, and incentives that reduce barriers to affordable and accessible SCD treatments and resources for vulnerable communities. This is an example of one type of collaboration patient advocacy groups can follow: commissioning the review of data to gather insights about its most vulnerable groups.

Attendees participated in breakout groups and discussed health equities and access to care. Patient groups noted health inequities their community faces. Payers acknowledged areas for improvement to address health equity. Below is a summary of the key takeaways discussed across the three groups.

#### Opportunities for Payers and Patient Advocacy Organizations to Address Health Equity

- 1) Ensure P&T committee is diversely represented and invite, if possible, patient advocacy group leaders to join to ensure patient perspective is represented.
- 2) Identify ways to build health plans with a health equity lens.
- 3) Patient advocacy groups can reach out to payers directly to identify ways that patient-reported outcomes may be collected to better understand the barriers to access to care that underrepresented groups face.
- 4) Work with Centers of Excellence network, if applicable, to collect data about community and subcommunities to better understand health equity-related challenges.
- 5) Work with value assessment agencies, like ICER, to share the patient experience as it relates to health equity challenges.
- 6) Patient advocacy groups can help assist payers to expand "geo access footprint" to get better access to care, specialists, and centers of excellence. Specifically, to work together to identify inadequacies within networks and either add appropriate providers to the network and/or arranging for specialists to run virtual clinics.
- 7) Provide additional formal meetings between patient advocacy groups (collectively) and payers (VBCDC like format, focusing on health equity).
- 8) Opportunity to continue education about disease state and in general, health equity for all stakeholders.

## Participants

### 4.1 Patient Advocacy Participants

(AiArthritis) International Foundation for Autoimmune & Autoinflammatory Arthritis

American Thrombosis & Hemostasis Network (ATHN)

CAD Foundation

Cystic Fibrosis Foundation

Comprehensive Health Education Services

Crohn's & Colitis Foundation

Hemophilia Alliance

Hemophilia Federation of America (HFA)

Huntington's Disease Society of America (HDSA)

Immune Deficiency Foundation (IDF)

Leukemia & Lymphoma Society

Little Hercules Foundation

Lupus and Allied Diseases Association

Multiple Sclerosis Association of America (MSAA)

National Eczema Association (NEA)

National Hemophilia Foundation (NHF)

Pulmonary Hypertension Association

Sick Cells

Susan G. Komen

### 4.2 Payer Participants

BCS Financial Corp.

Blue Cross Blue Shield Texas

CareSource

Cooperative Benefits Group (Former Haven, MagellanRx, and SelectHealth)

Enlightenment Bioconsult, LLC

Highmark

JTKenney, LLC

MMDLopes, LLC (Former CMO: Horizon BCBSNJ, EmblemHealth, and MagellanRx)

Sharp Health Plan, Health Services

FOR MORE INFORMATION, OR TO JOIN THE VBCDC CONVERSATION, PLEASE CONTACT:  
[VBCDC@Impactedu.net](mailto:VBCDC@Impactedu.net)