

**WEBINAR SERIES ON VALUE ASSESSMENTS
FOR SICKLE CELL DISEASE**

**PART 2:
“DRUG PRICING & COVERAGE DECISIONS”**

December 13th, 2019



WHO WE ARE

- **Sick Cells** is a non-profit organization that seeks to **elevate the voices** of the sickle cell disease (SCD) community and their stories of resilience.
- We work with fellow allies across the country to influence policy makers, educators, employers, healthcare administrators and healthcare providers to act to improve treatment and care for the SCD population.





WEBINAR SERIES

Sick Cells is hosting a four-part webinar series on:

VALUE ASSESSMENTS FOR SICKLE CELL DISEASE

- PART 1: FDA Approval, Now What? Friday, December 6th
- PART 2: Drug Pricing & Coverage Decisions Friday, December 13th
- PART 3: Examining the “Cost” of SCD Friday December 20th
- PART 4: Call to Action During the ICER Review Friday, January 10th



OBJECTIVES

PART 2: DRUG PRICING & COVERAGE DECISIONS

Today we will discuss:

- the ways drugs are sold and distributed
- the stakeholders involved and their impact on drug pricing
- how value assessments may influence drug pricing and coverage decisions

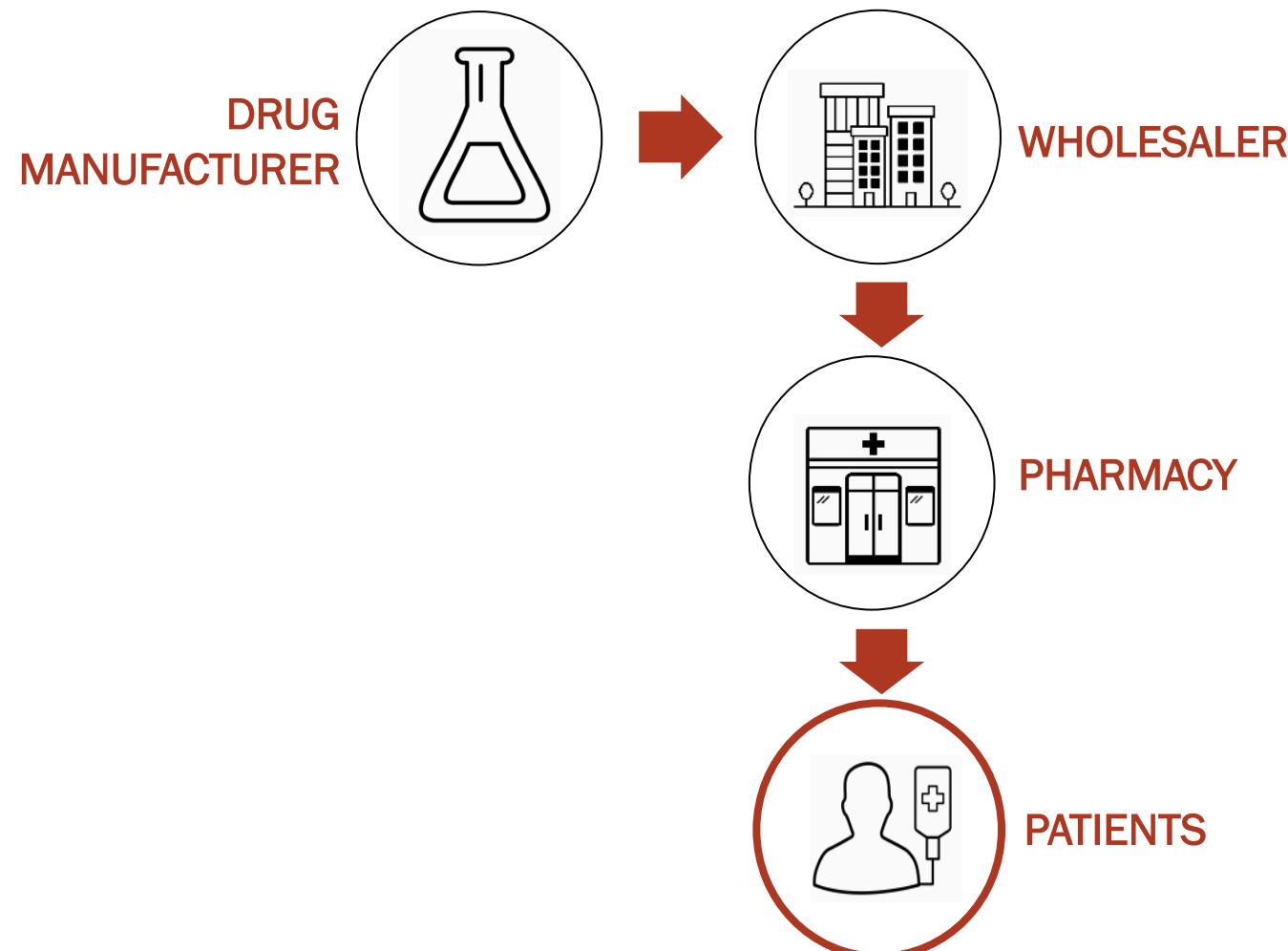
This webinar series is intended to:

- Answer common questions about the cost of medicine
- Advance a dialogue on how we can ensure SCD medicine is affordable for patients

HOW DRUG DISTRIBUTION AND PAYMENT WORKS

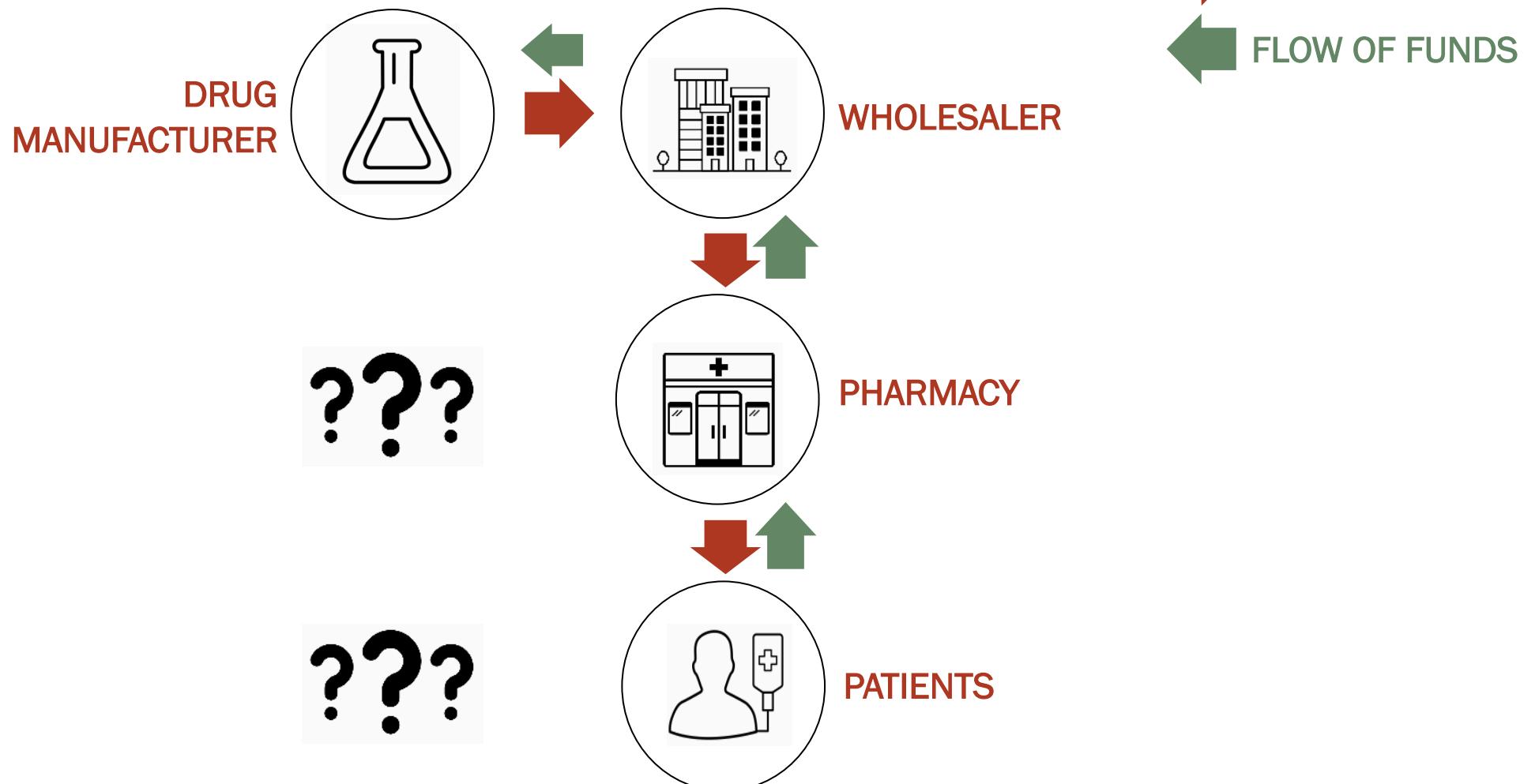
HOW DO DRUGS REACH PATIENTS?

→ FLOW OF DRUGS

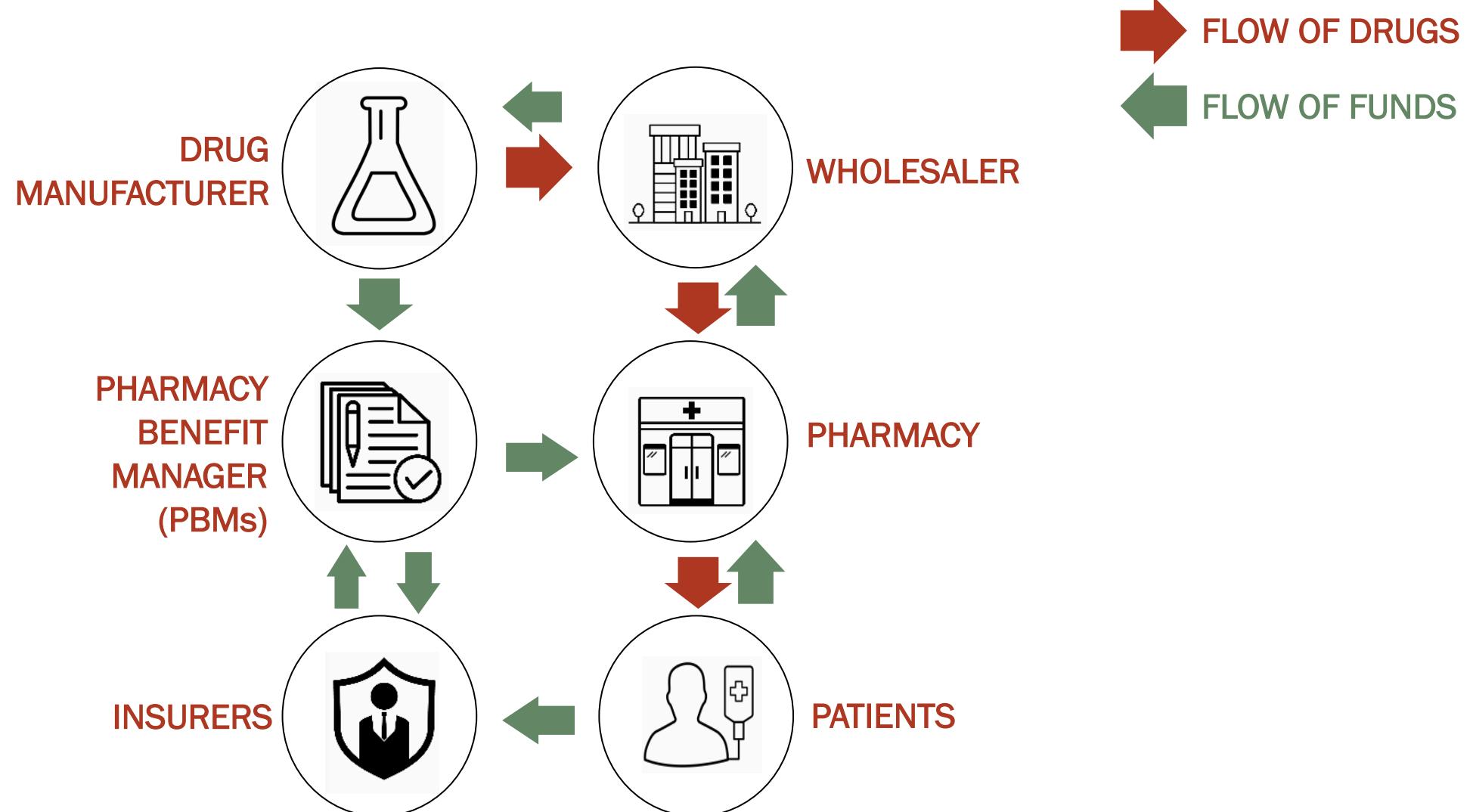


HOW DRUG DISTRIBUTION AND PAYMENT WORKS

HOW DO DRUG PROFITS FLOW?



HOW DRUG DISTRIBUTION AND PAYMENT WORKS



LIST PRICE VS NET PRICE

- Today, much of the public debate surrounding the cost of medicine is focused on the **list price** of an individual drug.
- The **list price** of a drug is the price a drug manufacturer initially sets.
 - The list price is **not** what a manufacturer generally makes on the drug.
- The **net price** is the actual amount that the manufacturer recoups from selling their product, once fees to various stakeholders are taken out
 - **Rebates and discounts** occur in a number of ways.

REBATES, DISCOUNTS, AND PROFITS

DRUG MANUFACTURER

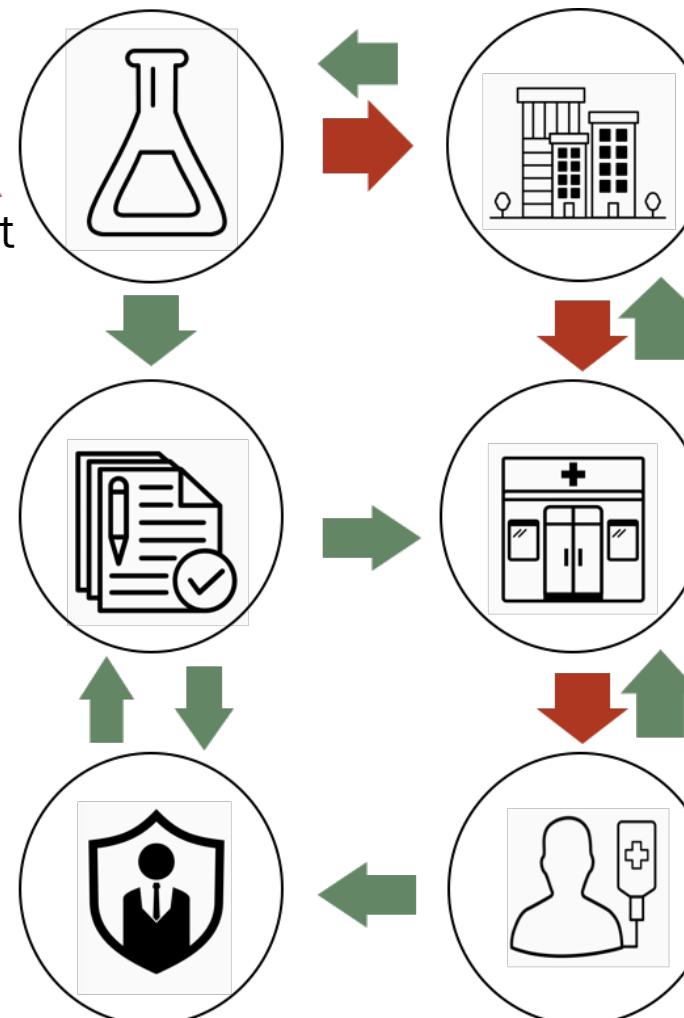
Drug manufacturers receive lower profit than the list price due to discounts and rebates.

PHARMACY BENEFIT MANAGER (PBMs)

PBMs are hired by insurers to negotiate a rebate from the drug manufacturer. PBMs may pass some of the rebates on to your insurer, or keep it as profit.

INSURERS

Insurers collect a premium from individual patients. Insurers agree to pay a part of the cost of drugs, and sets the patient's copayment.



WHOLESALER

Wholesalers negotiate discounts off the list price. Then, they mark up the drug and sell it to a pharmacy.

PHARMACY

Pharmacies collect reimbursement from PBMs and charge dispensing fees.

PATIENTS

Patients pay out-of-pocket prices (copays and deductibles).

WHAT IS THE IMPACT ON DRUG PRICES?

1. Increased transparency is needed to understand the impact on drug pricing.
 - Drug manufacturers are responsible for setting prices for prescription drugs
 - However, there are areas in the existing system that enables other stakeholder to keep prices high.
2. Increased drug prices allows the drug manufacturer to offer bigger rebates to the PBMs.
 - Then, the PBM in turn covers their drug on the formulary.
 - However this may be driving drug prices up.

WHY ARE SOME DRUGS MORE EXPENSIVE THAN OTHERS?

Generic vs. Brand-Name Drugs

- The company that develops a new medicine has patent protection
- Generic drugs can only be manufactured and sold once the patent has expired.

Biologics vs. Small Molecule

- In the past, medications had relatively simple chemical structures.
- Biologic drugs like monoclonal antibodies are complex, and manufacturing them results in a costlier process.

Research and Development

- A huge level of investment is required to bring forth new medicines.
- R&D costs include studies to test new indications, formulations, dosage strength and regimens, and to monitor safety and long-term side effects.



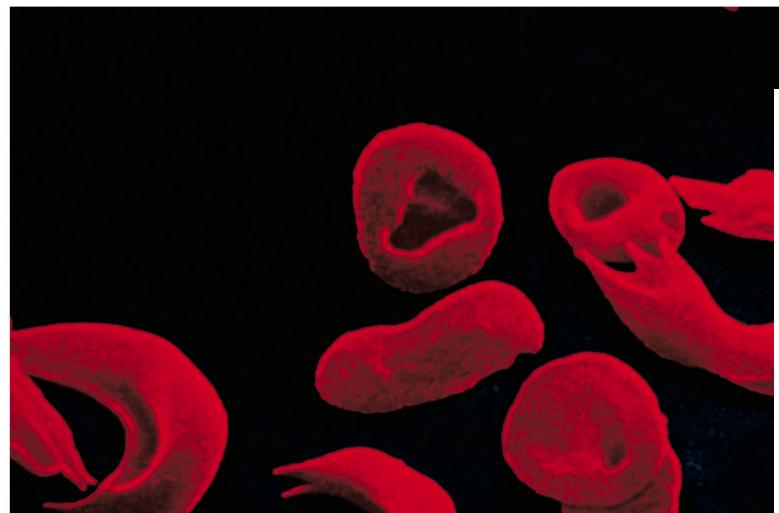
VALUE-BASED DECISIONS

- Insurers and PBMs are adopting **value-based formularies** based on cost-effectiveness of treatments
- Additionally, drug manufacturers use cost-effectiveness analyses to determine the list price of their drugs.
- This links the overall payment for drugs to the **value** of the clinical outcomes they achieve.
- The goal of this is to ground decisions in **stronger clinical and economic evidence**.

WHY IS THIS IMPORTANT FOR SCD?

Two New Drugs Help Relieve Sickle-Cell Disease. But Who Will Pay?

Adakveo and Oxbryta could be revolutionary treatments, but each costs about \$100,000 per year and must be taken for life.



Source: www.nytimes.com

ICER to Assess Treatments for Sickle Cell Disease

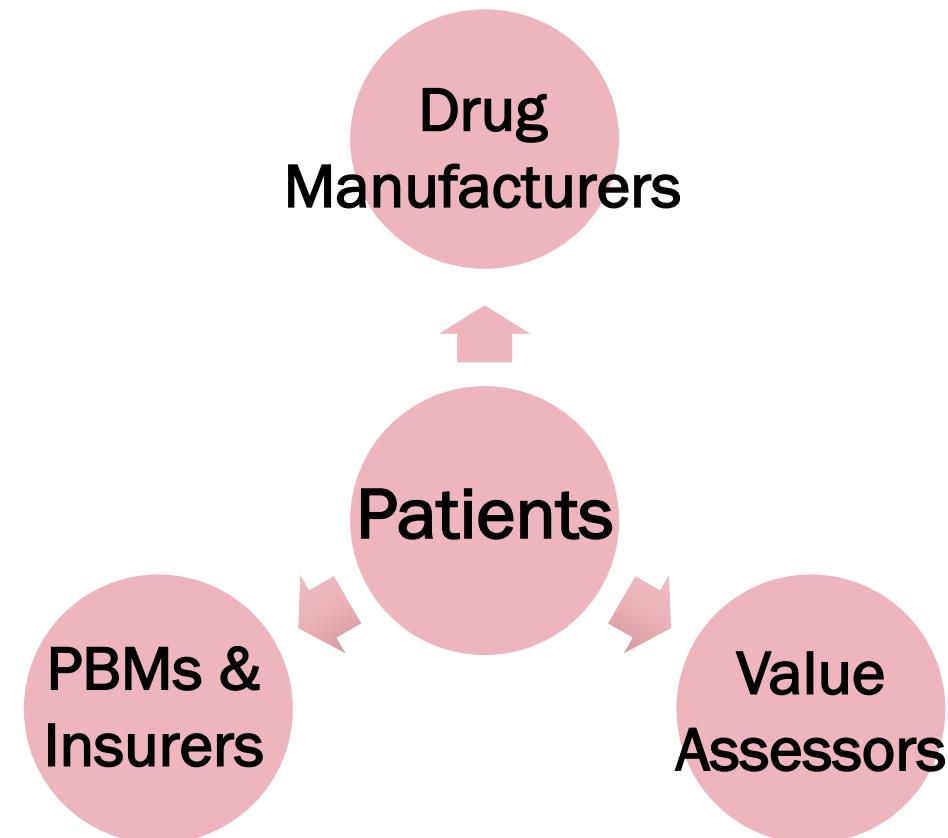
— Report will be subject of New England CEPAC meeting in March 2020; Open Input now being accepted until August 27, 2019 —

BOSTON, August 9, 2019 – The Institute for Clinical and Economic Review ([ICER](#)) announced today that it plans to assess the comparative clinical effectiveness and value of crizanlizumab (Novartis) and voxelotor (Global Blood Therapeutics) for the treatment of sickle cell disease.

Source: icer-review.org

WHAT IS OUR ROLE AS PATIENT ADVOCATES?

- To advocate for **fair drug pricing and coverage** by engaging with other stakeholders.



- Be armed with data and present your expertise.

STAY ENGAGED

- Join us during the next part of our webinar series:
PART 3: “Examining the Cost of SCD”
Friday, December 20th
- Stay tuned to our website and social media pages for more information including registration links
- Reach out to us at mjalowsky@sickcells.org



Q&A SESSION