



COMPASS: Guiding the Direction of Community Engaged Sickle Cell Disease Research

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OBJECTIVES



1. Define “Comparative Effectiveness Research”.
2. List 3 components of a Comparative Effectiveness Research question
3. List 2 ways CER relates to the Sickle Cell Community Consortium's current funded Patient Centered Outcomes Research Institute (PCORI) project.
4. List 2 comparators that may be important to the SCD community.

What is Comparative Effectiveness Research?



- [What is Comparative Effectiveness Research?](#)

What Is Comparative Effectiveness Research?



- **IOM:** “the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care”
- **FCC:** “the conduct and synthesis of research comparing the benefits and harms of different interventions and strategies to prevent, diagnose, treat and monitor health conditions in “real world settings”

What Is Comparative Effectiveness Research?



- **Comparators**

- **IOM:** “direct comparison of effective interventions”
- **FCC:** “comparator arms other than placebo”

- **Population**

- **IOM:** “typical day-to-day clinical care”
- **FCC:** “representative of populations seen in “real world practice”

Why Do Comparative Effectiveness Research?



- **IOM:** “assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at both the individual and population levels”
- **FCC:** “to improve health outcomes by developing and disseminating evidence-based information to patients, clinicians, and other decision-makers, responding to their expressed needs, about which interventions are most effective for which patients under specific circumstances”

Institute of Medicine. Initial National Priorities for Comparative Effectiveness Research. 2009; Federal Coordinating Council. For Comparative Effectiveness Research. Report to the President and the Congress June 30, 2009

Tufts | CTSI

Tufts Clinical and Translational Science Institute
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Community Engagement



Result of Stakeholder Engagement?



- Data, information or findings resulting from the involvement in research activities of certain individuals or groups.

"Nothing for us, without us".



COMPASS

COMPASS: COMMunity Participation to Advance the Sickle cell Story

COMPASS: Background



- “Nothing for us, without us”
- \$50,000 Cooperative Agreement
- Patient Centered Outcomes Research Institute (PCORI)
- “Tier A” Award
 - Not Research
 - Designed to support the **development of research partnerships** as they identify a comparative clinical effectiveness research (CER) question (or series of questions) that is important to patients, researchers, and other members of the healthcare community.

COMPASS: Purpose



- To engage the Sickle Cell Community Consortium's (SCCC) national network of patients, caregivers and community-based organizations (CBOs) to **capture patient-defined research priorities to bridge the gap between research, practice, and true outcomes (change) for individuals living with sickle cell disease (SCD).**

COMPASS: Objectives



- Create a **survey** to capture patient/caregiver perspectives
- **Engage** and **educate** the patient/caregiver community through online **webinars** and **in-person** during the 3rd annual Sickle Cell Community Consortium Leadership Summit & General Assembly of Patients, Caregivers and CBOs, the 5th annual Sickle Cell Patient & Family Education Symposium, and during the Consortium partner regional Symposiums
- Build upon pre established/new **partnerships**
- Generate a **list of patient generated research priorities and CER questions through engagement, education, and empowerment**



What are the **comparative benefits and risks** of **nursing home, assisted living, and home-based care** for **older adults with dementia**?



PEOPLE: the group of people to be studied

OPTIONS: the choices or options that should be compared

OUTCOMES: what good and bad things a patient can expect from each option to help them make a decision

CER Projects Across the Country



[Community Health Workers and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care \(COMETS Trial\)](#)

The Childrens' Hospital of Philadelphia; David M. Rubin, MD, MS

[Comparative Effectiveness of a Decision Aid for Therapeutic Options in Sickle Cell Disease](#)

Emory University; Lakshmanan Krishnamurti, MD

CER Projects Across the Country



Comparative Effectiveness of Peer Mentoring versus Structured Education-Based Transition Programming for the Management of Care Transitions in Emerging Adults with Sickle Cell Disease

Atrium Health/Levine Cancer Institute; Ifeyinwa Osunkwo, MD, MPH; Raymona H. Lawrence DrPH, MPH, MCHES

Comparing Patient Centered Outcomes in the Management of Pain between Emergency Departments and Dedicated Acute Care Facilities for Adults with Sickle Cell Disease

Johns Hopkins University; Sophie Lanzkron, MD, MHS

CER Projects Across the Country



Engaging Parents of Children with Sickle Cell Anemia and their Providers in Shared-Decision Making for Hydroxyurea

Cincinnati Children's Hospital Medical Center; Lori E. Crosby,
Psy.D



Warrior/SCD Stakeholder- Specific CER Questions

SCD Stakeholder-Generated CER Questions



- What is the comparative effectiveness of **alternative therapy (e.g., breathing exercises, yoga, mindfulness)** vs. **opioid use** on **pain outcomes** in **individuals with SCD who have chronic pain and are at least 13 years of age?**

SCD Stakeholder-Generated CER Questions



- What is the comparative effectiveness of **various modalities (online vs face-to-face and individual vs. group)** of mental health services on **pain outcomes** in **individuals with SCD who have chronic pain and are at least 13 years of age?**

Did We Get it Right?



How are you seeing this situation? *I understand*
I get that. What can we do about this? Why did that upset you? I'm feeling

COMPASS: What's Next?



- **Survey**
- **Findings will be used to inform researchers, physicians, policy makers, funding agencies, community based organizations and other entities about the research needs of sickle cell patients using the patients' VOICE and prepare sickle cell CBOs for participating in CER research projects.**
- **Pursue outside funding**

Resources for Learning about CER and Engagement



- PCORI
 - <https://www.pcori.org/>
- Tufts Clinical and Translational Science Institute
 - <https://ilearn.tuftsctsi.org/>
- Trailhead INSTITUTE
 - <http://www.trailhead.space/webinar-blog>

Thank you for being the **COMPASS** for future
SCD research!!



**Sickle Cell
Disease/Anemia**