



# Evaluating Research Equity, Accessibility, Diversity, and Inclusion Programming for Translational Science Benefits

March 9, 2023

1:45PM-2:45PM (CST)



CLINICAL AND  
TRANSLATIONAL  
SCIENCE COLLABORATIVE



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**March 9, 2023**

**1:45PM-2:45PM (CST)**

**Clara Pelfrey, PhD, Evaluation Director, CWRU CTSC**

**Gelise Thomas, JD, MS, Assistant Director, Strategic DEI & Health Disparities, CWRU CTSC**

# The Big Picture

Mission: Health  
Equity  
Challenge  
Series



Research Policy  
Impact

### Translational Science Benefits Model (TSM)

CLINICAL	COMMUNITY	ECONOMIC	POLICY
<b>Clinical &amp; Medical Benefits</b> (Procedures, clinical guidelines, tools, devices & products)	<b>Community &amp; Public Health Benefits</b> (Health activities, care, programs and health promotion)	<b>Economic Benefits</b> (Commercial products, financial savings and benefits)	<b>Policy &amp; Legislative Benefits</b> (Advisory activities, policies & legislation)

Special Populations  
Roundtable Talks

### Current Trauma

- 2016
  - Affordable Care Act - Obama Care
  - Black Lives Matter
- Black life expectancy dropped
  - 75 years to 72 years more than 2.7 years
  - Lowest since 2001
- COVID-19 had had a detrimental impact on the black community
  - 2.9 times the rate of whites to be hospitalized
  - 1.9 more likely die than white American
  - 2.4 rate of African American youth orphaned
- Anti-racism in hospital settings
- Menthol restrictions

Community  
Engagement



### Example Videos

Heritage and Awareness  
Months

# Logic Model

## INPUTS

What we invest

- Partnerships w/external organizations
- CTSC personnel



## ACTIVITIES

What we do

- Screen film
- Discuss book
- Host panel
- Organize un-meeting
- Evaluate programming



## OUTPUTS

Products, services, events intended to lead to outcomes

- # participants
- # event attendees
- # repeat attendees
- # follow-up events
- # resoures shared by participants
- # opportunities offered by presenters/panelists



## OUTCOMES

Changes in learning, action, conditions

Short Term  
Changes in learning

Mid-Term  
Changes in action

Long Term  
Changes in conditions

Overall + CTSC  
-Visibility  
-Community-building

Overall + CTSC  
-More HD programming

Overall + CTSC  
-Research collaborations

Researchers  
-Felt program met objectives  
-Know more HD  
-Inc. knowledge re: bias

Researchers  
-Sign up for more sessions  
-Schedule a READI appt.  
-Take addtl. HD training  
-HD grant proposals  
-More publications re: HD

Researchers  
-More participant diversity  
-More diverse research teams  
-> research addresses HD  
-More research grants funded  
-Pubs used in policy docs

Community Members  
-More knowledge  
-Field questions

Community Members  
-Participate in CABs, IRBs  
-Participate in grants, pubs

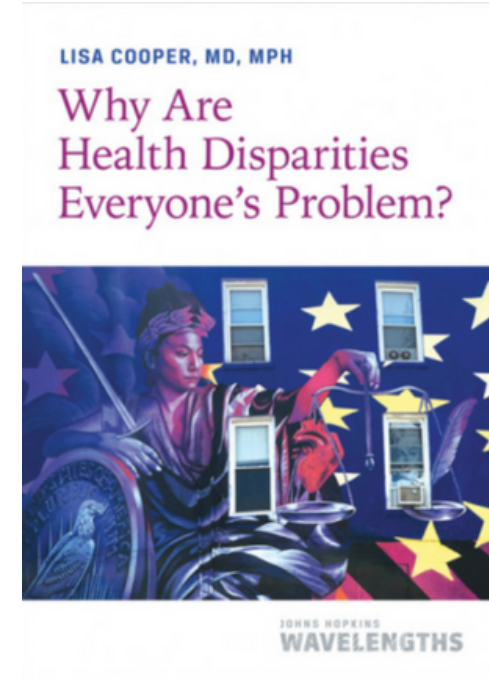
Community Members  
-Local care improvement  
-Community researchers  
-Co-author opps

Health Providers  
-Inc. knowledge of how bias affects HD

Health Providers  
-Mobile healthcare units  
-Screenings + food pantry events

Health Providers  
-Get involved in health disparities studies  
-Increase collaborations with HD researchers

# Timeline



Sep. 2022-present

Oct. 2022-Dec. 2022

Jan. 2023

March 2023

**Challenge #1: Film  
Screenng**



*The Color of Care*

**Challenge #2: Book  
Discussion**

*Why Are Health Disparities  
Everyone's Problem?* by Lisa  
Cooper, MD, MPH

**Challenge #3: Community  
Organization Research  
Experience Panel**



**Challenge #4: Health  
Disparities Un-Meeting**

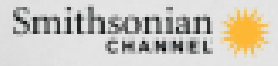
250+ registrants nationwide  
to date

# The Ripple Effect





EXECUTIVE PRODUCER  
OPRAH WINFREY



# THE COLOR OF CARE

NOT ALL HEALTHCARE  
IS CREATED EQUAL



LISA COOPER, MD, MPH

# Why Are Health Disparities Everyone's Problem?



JOHNS HOPKINS  
WAVELENGTHS



7th Annual Cancer Disparities Symposium



Health Professions Case Study





# Community Organization Research Experience Panel



Greater Cleveland  
Food Bank

Cleveland  
Neighborhood  
Progress



<https://youtube.com/@CWRU-CTSC>

# Research Policy Impact Series

How do we improve evaluating and communicating the Health and Societal Benefits of Clinical and Translational Sciences?

Start the research planning with the IMPACT in mind!

## READI Research Policy Impact

CTSC Cleveland

1 video No views Last updated on Feb 8, 2023

1

How do we improve evaluating and communicating the Health and Societal Benefits of Clinical and Translational Sciences?

Start the research planning with the IMPACT in mind!

55:58

**Pilots and Beyond: CTSC Research Impact on Legislative, Regulatory or Practice Policies (01/10/23)**

CTSC Cleveland • 61 views • 1 month ago



CTSC Research Impact on Legislative, Regulatory or Practice Policies




Health Policy 101



A Local Perspective: Medical Research as a Tool for Influencing Public Policy



# Special Populations Roundtable Talks



**READI Special Populations Roundtable Talks**

CTSC Cleveland  
2 videos · 7 views · Last updated on Feb 24, 2023

Play all Shuffle

- 1  **READI Special Populations Roundtable Talks: People with Physical Disabilities (01/27/23)**  
CTSC Cleveland · 32 views · 1 month ago · 53:31
- 2  **READI Special Pops Roundtable Talks: Race/Ethnicity-African American and Black Community (02/24/23)**  
CTSC Cleveland · 43 views · 12 days ago · 47:26



## Race/Ethnicity:

- Black, African American
- Ancestry and Health Disparities
- Hispanic and Latino/a



## Geography: Rural



## Disabilities:

- Physical
- Communication Disorders and Deaf/Hard of Hearing
- Intellectual
- Invisible

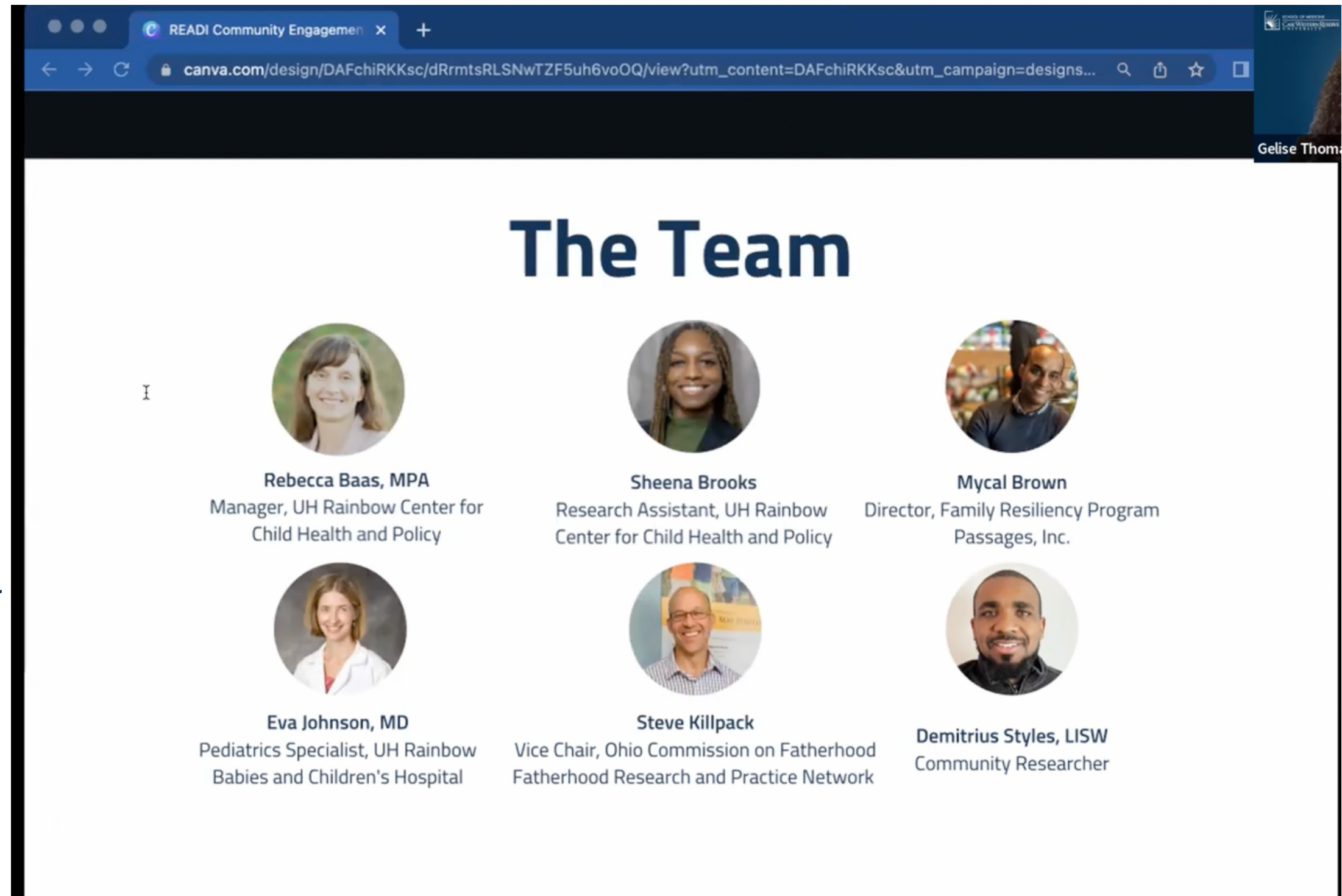
# Community Engagement

## Equity in Engagement:

- How to Engage Community Members as Researchers
- Building Relationships with Community Health Workers to Advance Research

## Getting Involved:

- Becoming a Community Researcher
- Community Advisory Boards and Institutional Review Boards



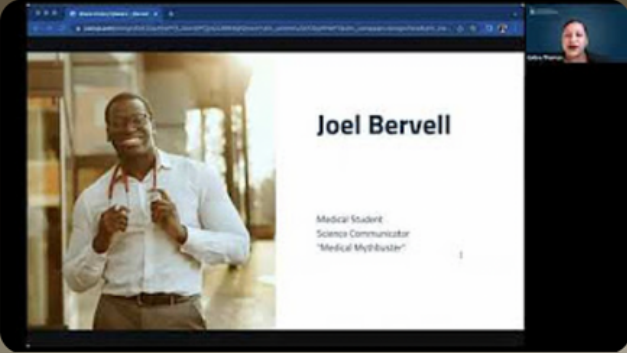
Caption: Image from *Equity in Engagement: How to Engage Community Members as Researchers*

# Heritage and Awareness Months



This was an excellent presentation. Very impressed with the passion shown and the work being done to honor these women [Mothers of Gynecology] and showcase the ethical dilemmas related to disparities that could potentially still exist. Thank you!

[quote from attendee of Michelle Browder's talk - Black History Makers series]







**Black History Makers Series**

CTSC Cleveland  
4 videos 60 views Last updated on Feb 23, 2023

Play all Shuffle

Each week of February 2023, we heard from a local or national Black History Maker (BHM) advancing health equity.

-  **Black History Makers 2023: Joel Bervell (02/02/23)**  
CTSC Cleveland • 118 views • 1 month ago
-  **Black History Makers 2023: Randy Vince, Jr., MD, MS (02/09/23)**  
CTSC Cleveland • 31 views • 3 weeks ago
-  **Black History Makers 2023: Michelle Browder (02/16/23)**  
CTSC Cleveland • 112 views • 2 weeks ago
-  **Black History Makers 2023: Linda Bradley, MD (02/23/23)**  
CTSC Cleveland • 12 views • 13 days ago



**Fireside Chats with Leading Ladies**

CTSC Cleveland  
2 videos 11 views Updated 5 days ago



# Challenges



Inconsistency  
in data  
collection



Capacity

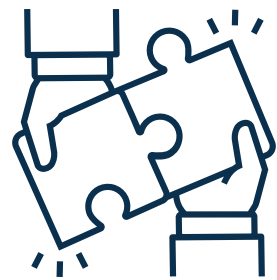


Lack of  
documentary  
ownership to  
confirm virtual  
viewership



Promotion for  
voluntary  
events

# Opportunities



Co-creation amongst partner affiliates for second year



Improved data collection by streamlining REDCap efforts



Targeted marketing with a theme (i.e., Women's Health Equity - OBGYN departments)



Provision of CME credits to attract greater participant diversity (e.g., men)

# Key Takeaways

A high-speed photograph of a water droplet falling into a pool of water, creating a series of concentric ripples. The droplet is captured mid-fall, just above the surface, with a smaller droplet trailing behind it. The ripples are clearly visible, spreading outwards from the point of impact. The background is a soft, out-of-focus light blue.

- Show and tell
- Meet people (or organizations) where they are
- Start with evaluation in mind
- Find comfort in the unknown
- The ripple effect knows no boundaries



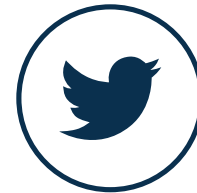
# Acknowledgments



# Thank You For Joining Us



[case.edu/medicine/ctsc](https://case.edu/medicine/ctsc)



[@CTSC\\_Cleveland](https://twitter.com/CTSC_Cleveland)



[linkedin.com/in/ctsc-cleveland](https://www.linkedin.com/in/ctsc-cleveland)



[ctsc-administrator@Case.edu](mailto:ctsc-administrator@Case.edu)

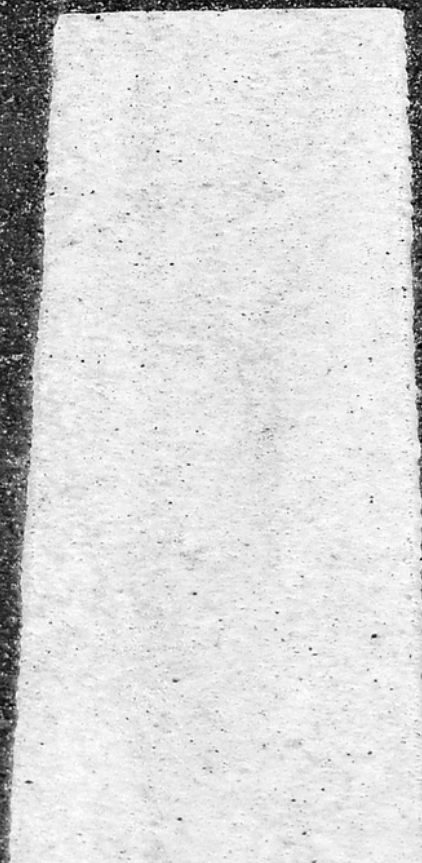


[@CWRU-CTSC](https://www.youtube.com/@CWRU-CTSC)

**Policy**




**Research**



**Policy**



**Research**



# Evaluating READI Programming and Demonstrating Translational Science Benefits

**Clara Pelfrey, PhD**

Evaluation Director

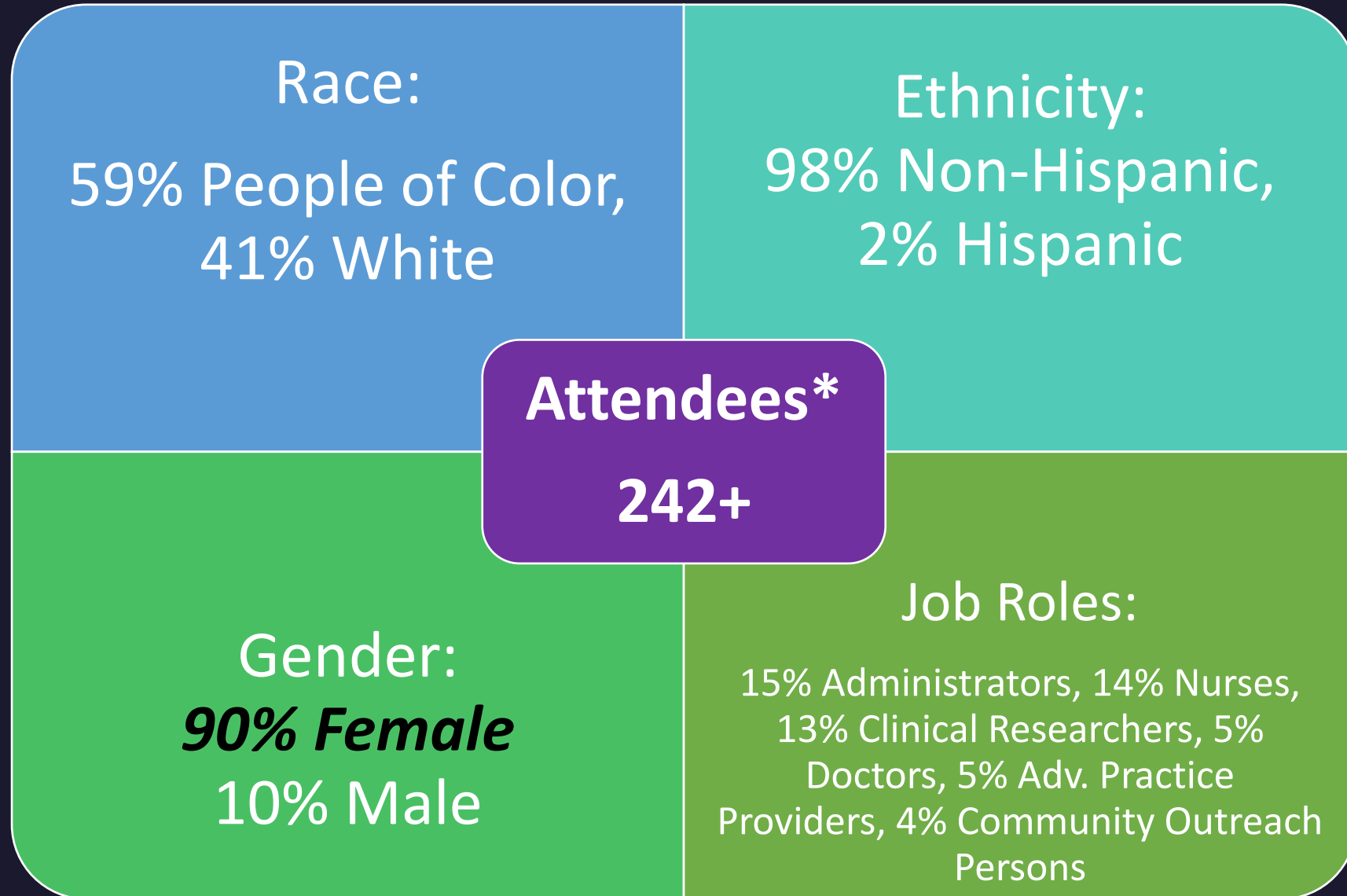
Clinical and Translational Science Collaborative  
(CTSC), Case Western Reserve University

# Agenda

- Evaluating health equity programming
- Evaluating impact using TS case studies
- Researching publications to uncover policy impact
- Using the TSBM to understand community health benefits of trainee research



# The Color of Care Film Screenings - demographics

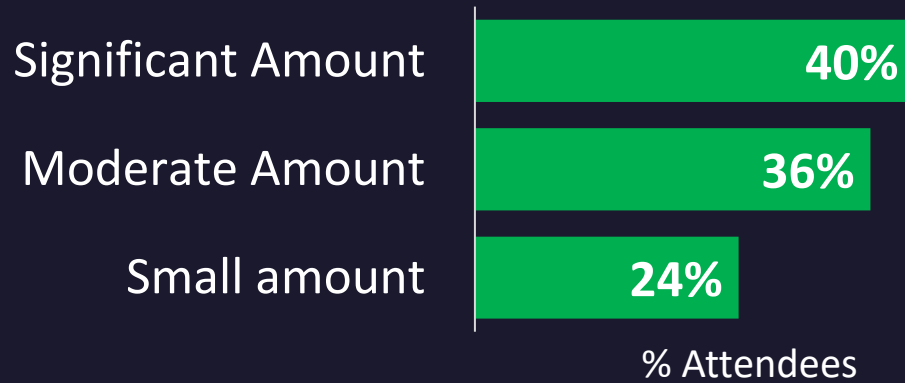


\* An additional 819 registrants at the Cleveland Clinic

# Learning about health disparities

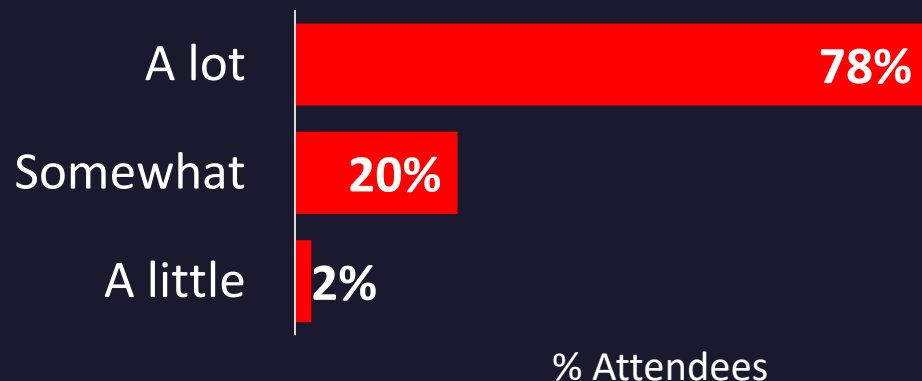
n=86 (36% response rate)

How much *new information* did you learn about **health disparities**?

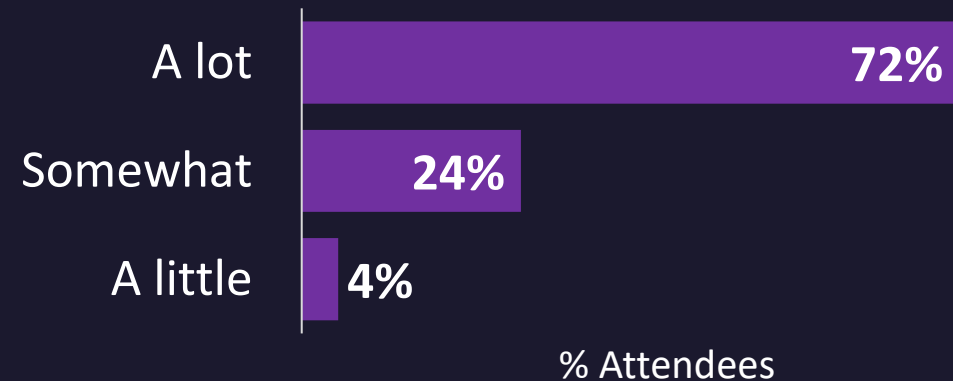


**76%** said they learned a moderate or a significant amount about health disparities

Understand the **roots of distrust** of the medical community?



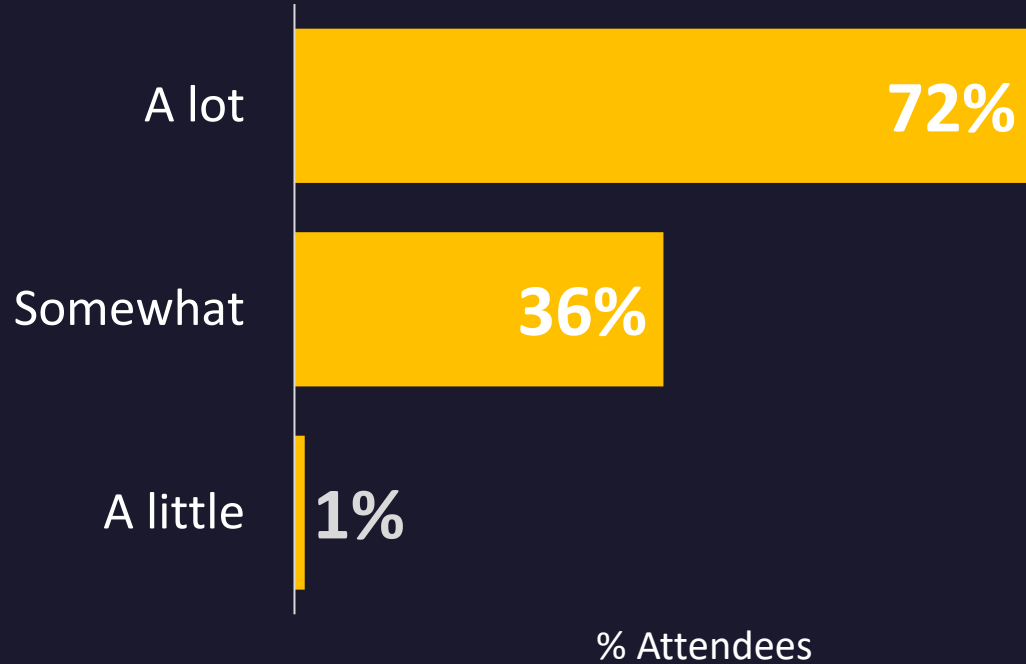
Comprehend the difference between **equality and equity**?



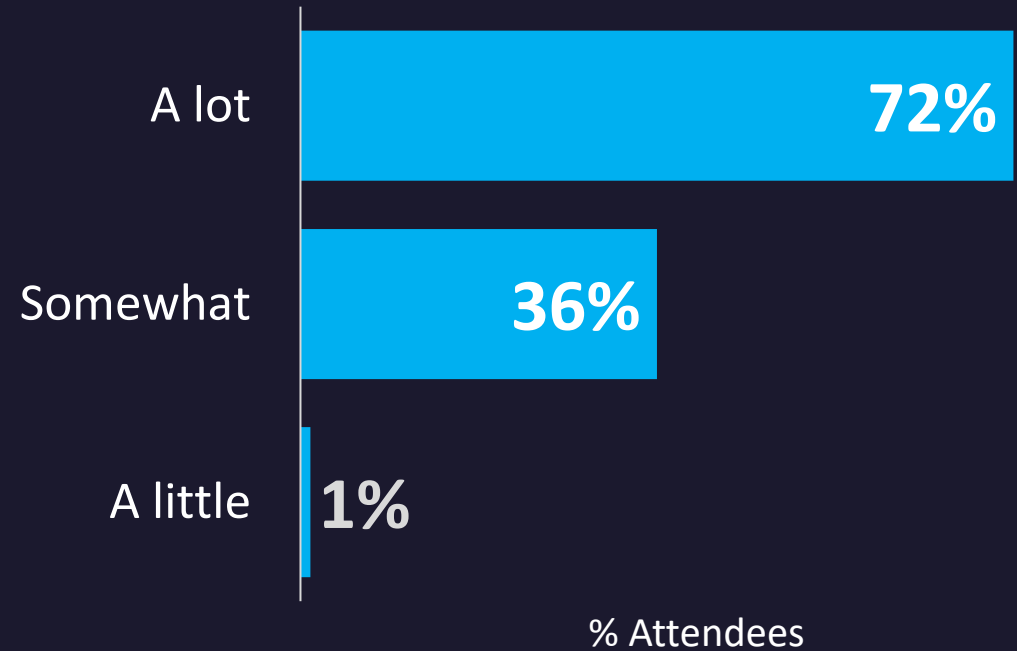
# Racial Bias

n=86

## Able to recognize racial bias?



## Familiar with ways to remediate racial bias?

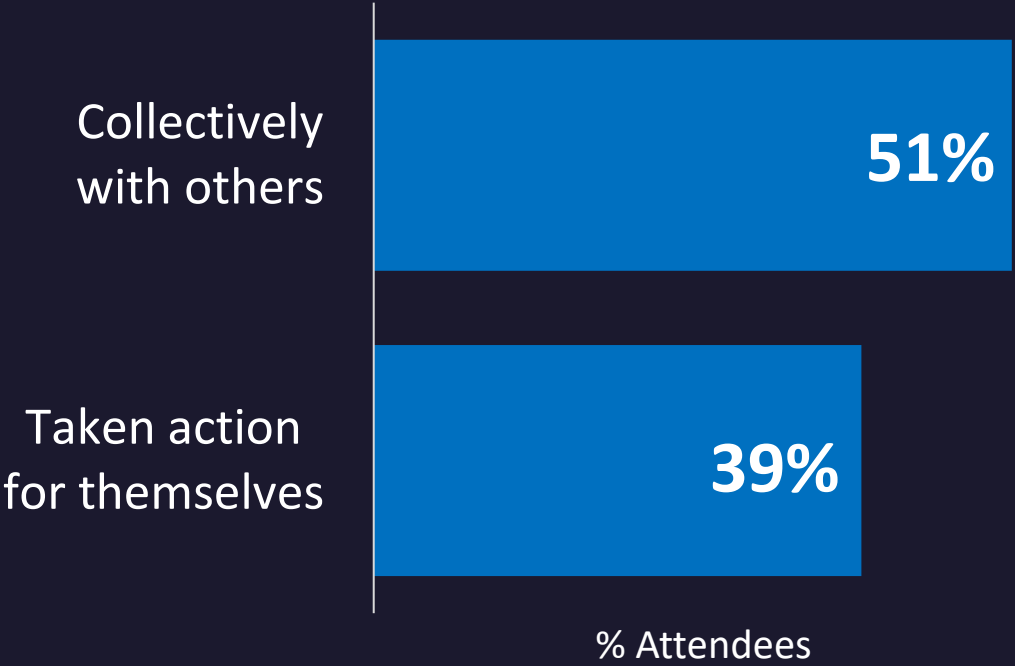




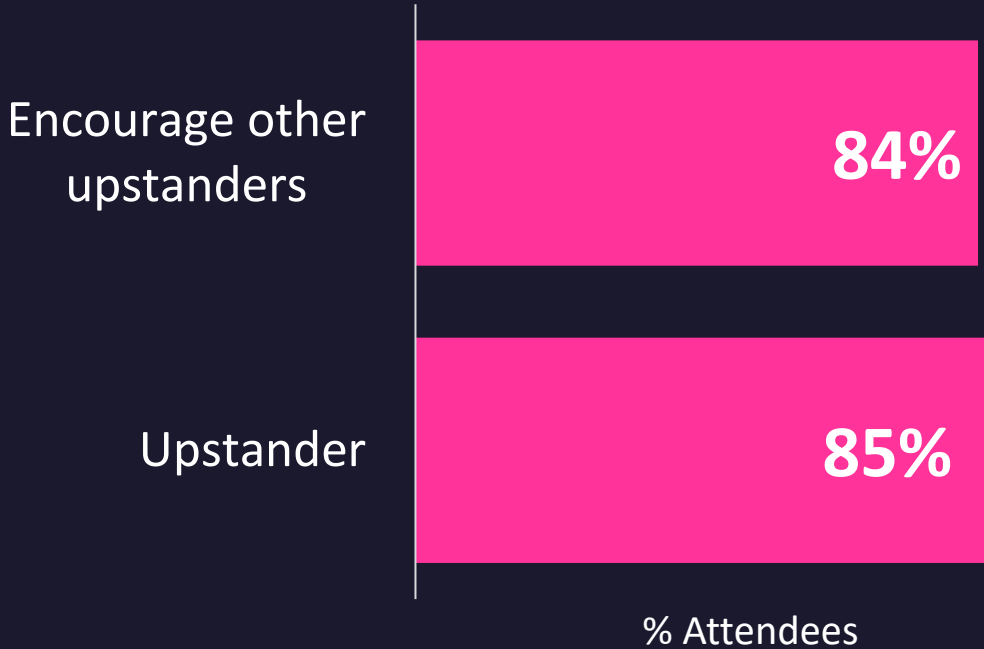
# Changed Behavior

n=85

Have you taken any action to mitigate health inequities?



Being/encouraging being an upstander?



# Color of Care Film Screening

## How people are being an Upstander?

n=46

“As part of a community outreach team I am encouraging events in areas that might not otherwise have access to free health screenings. We are in the process of setting up free screenings in conjunction with food pantry pick up. As we know transportation can be a hurdle for many --- so if they are already there picking up pantry items why not offer free health screenings? Fingers crossed we can build trust and provide a good resource for many.”

“I work to use the power and privilege I have to elevate, to invite others into decision making spaces when I can and work to continue learning where my blind spots are.”

“I show up at community events and are there for patients with multiple needs beyond the office visit. I make an effort to engage patients to choose for themselves.”

“Recognizing and openly commenting on potential biases or perceived moments of doubt in a fashion that otherwise could've been considered "taboo" to address. Speaking up with as much humility and well-intentions as possible throughout the work life.”

# Health Disparities Book Discussion-

## How people are being an Upstander...

n=6

“Speaking with people so that they're comfortable standing up for themselves and others when witnessing inequities.”

“For myself, family, friends, students, and peers that I work with I first, try to help them understand the disparities that they may be feeling and that it is not in their imagination and then giving them information based on the book or on the website to help them navigate different situations..”

“I sought out and planned a training for being an upstander for the national organization I work for. I also work to educate people in my everyday interactions about how pervasive racism is.”

“I am using the "Five Miles Apart" story from Lisa Cooper's book to help teach about health disparities and how they can stem from historical events and social structures. I am facilitating a session with up to 9 different types of health professions education students (over 500 students) in the Collaborative Practice 1 class..”

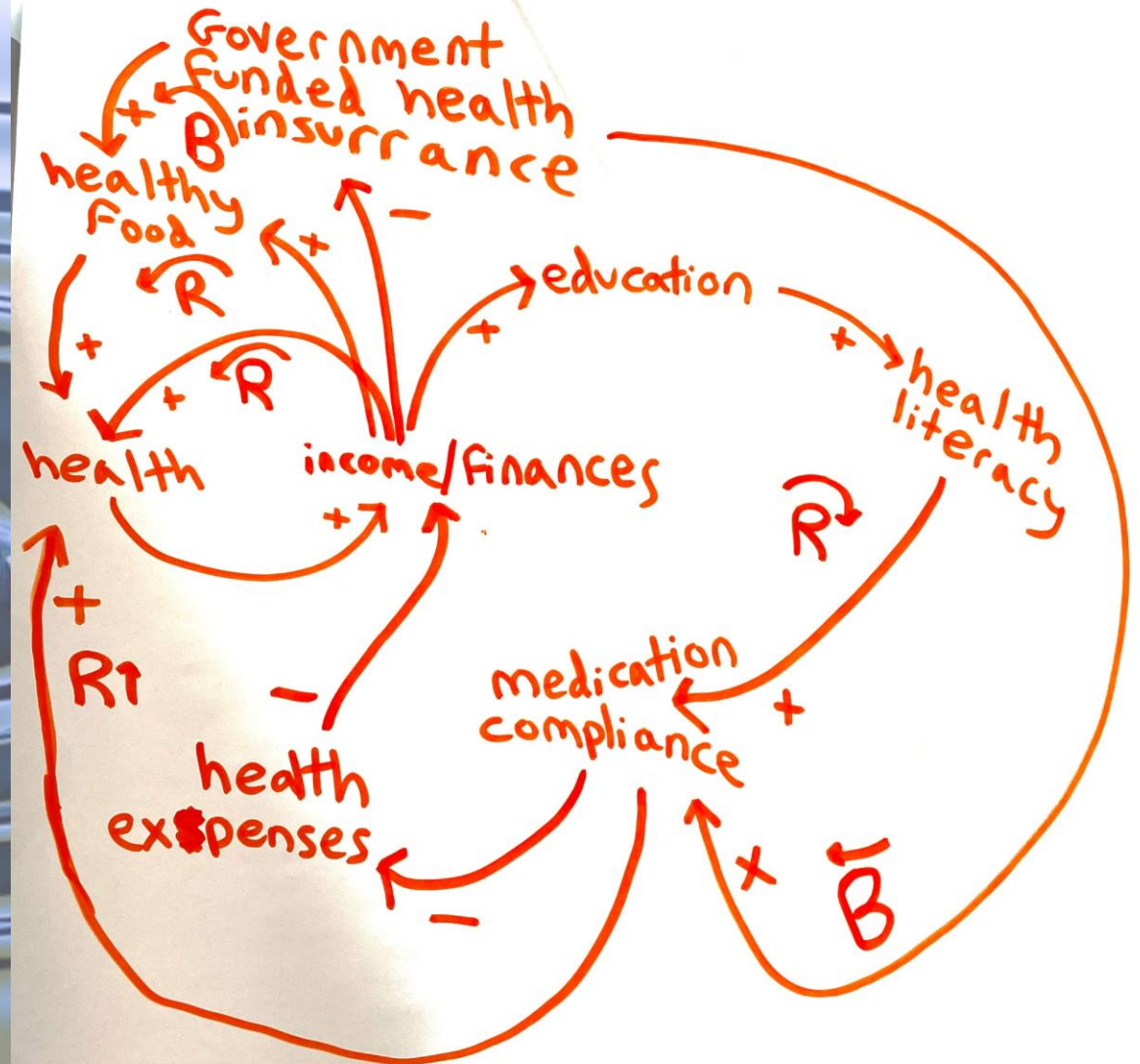
# The Ripple Effect

## Systems Thinking

Health Professions Education students created this Closed Loop Diagram of a real-life case study about health disparities

### Closed Loop Diagram

C12





# Research to Practice to Policy

Dr. Umut Gurkan

## A Retrospective Case Study of Successful Translational Research: Gazelle Hb Variant Point-of-Care Diagnostic Device for Sickle Cell Disease

Published online by Cambridge University Press: 25 October 2021

Kelli Qua , Shannon Swiatkowski, Umut Gurkan and Clara M. Pelfrey 

April 2020 Analyst Journal cover  
Royal Society of Chemistry  
Paper-based microchip electrophoresis for point-of-care hemoglobin testing

# Research to Practice: Sickle Cell Diagnostic Milestones

## EVIDENCE OF IMPACT ON HUMAN HEALTH



DR. UMUT GURKAN

2014

**HemeChip laboratory prototype developed**

1<sup>st</sup> proof-of-concept laboratory prototype was developed in Dr. Gurkan's laboratory at CWRU

12/2015

**1<sup>st</sup> international conference presentation of the laboratory prototype and preliminary results**

1<sup>st</sup> public disclosure of the technology at American Society of Hematology Annual Meeting

5/2016

**HemeChip was licensed to Hemex**

Included all microchip electrophoresis applications

2014

12/2017

**1<sup>st</sup> clinical study in Africa - Nigeria**

1<sup>st</sup> pilot clinical study in Africa was in Kano, Nigeria for sickle cell disease

3/2018

**1<sup>st</sup> clinical study Thailand**

1<sup>st</sup> study in Thailand for hemoglobin E disease

6/2018

**Vodafone Wireless Innovation Project Competition First Place**

\$300K for developing data connectivity over mobile networks

2018

**SMART: Sickle cell and Malaria Remote Accurate Testing**

For developing data connectivity over mobile networks

CTSA PROGRAM  
PILOT  
FUNDING WAS  
THE CRITICAL  
CATALYST

6/2017

**HemeChip functional product prototype developed**

1<sup>st</sup> prototypes of HemeChip were injected molded in Ohio and ran on a prototype reader designed by Hemex with a contract engineering company.

2017-2018

**Seed Funding**

Multiple angel groups and small VCs

Initial HemeChip Prototype

8/2018

**NIH/NIDDK Phase I STTR: Portable, affordable, quantitative microchip electrophoresis for hemoglobin A1C testing**

\$225K to explore additional test capabilities on HemeChip Platform

9/2018

**NIH/NHLBI Fast-track SBIR: Affordable, quantitative microchip electrophoresis for sickle cell disease screening**

\$1.7M to develop automated single step cartridge and additional clinical studies

12/2018

**Business Oregon Matching Grant for Fast-Track HemeChip SBIR: Enhanced Sickle Cell Disease Cartridge Automated Manufacturing Process**

\$150,000 to develop automated manufacturing process

12/2017

**Second international conference presentation of the product prototype and initial clinical study results**

First public disclosure of the product prototype and clinical validation results. Hemex with a contract engineering company



Gazelle Device

2020

**2<sup>nd</sup> clinical study in Africa - Ghana**

First clinical study in Africa with final reader and included newborns for sickle cell disease testing

2020

**3<sup>rd</sup> clinical study in Africa - Nigeria**

Validation study on large number of subjects and includes digital data transfer to the cloud

3/2020

**Cover article in Analyst journal**

A comprehensive description of diagnostic accuracy based on clinical validation studies performed in Nigeria, India, Thailand for hemoglobin variants

1/2019

**Series A Funding Achieved**

Led by strategic partner

5/2019

**1<sup>st</sup> clinical study in India**

First study in India was for sickle cell disease and sickle beta thalassemia

9/2019

**Manufacturing started in India**

Manufacturing is done by two contract manufacturers in India

9/2019

**CTIP: Consortium for Tech & Innovation in Pediatrics: Clinical Research for Breakthrough SCD Device**

\$45K for additional clinical studies

11/2019

**1<sup>st</sup> peer-reviewed publication (proof of concept)**

Presented and published as a conference proceeding of the 2019 IEEE Healthcare Innovations and Point of Care Technologies (HI-POCT) conference at the NIH

## GHANA, AFRICA



REAL WORLD TESTING WAS CRITICAL

Users provide feedback for design and development

2021

4/2020

**NHLBI Phase I STTR:**

**Portable, affordable, quantitative microchip electrophoresis system for integrated anemia and Hb variant testing**  
\$225K for adding anemia testing capability

9/2020

**NIH Technical Accelerator: Affordable, Non-Invasive and Minimally Invasive Diagnosis of Anemia, Malaria, and SCD**

\$100K for developing a non-invasive testing modality

10/2020

**1<sup>st</sup> sale of units**

1<sup>st</sup> reimbursement of reader by payers

6/2021

**Newborn screening test received regulatory approval**

1<sup>st</sup> worldwide remote software update expands patient age range from 6 weeks to all ages



INVESTING IN INNOVATION FOR UNDERSERVED POPULATIONS SAVES LIVES

# Research to Policy: How has CTSC-supported research improved human health and informed practice/policy?

One way is to evaluate *how published research findings are used to advance translation:*



**Academic citations**



**News & Media references**



**Patent references**

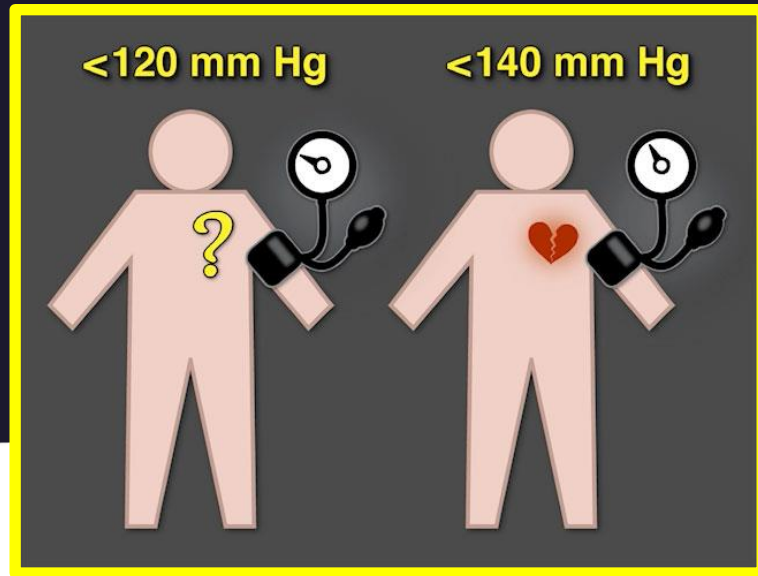


**Policy Document references**

overton

[www.overton.io](http://www.overton.io)

# The CTSC supported the SPRINT Trial



## Final results of SPRINT study confirm controlling blood pressure critically important in preventing heart disease and stroke

*UH Cleveland Medical Center and Case Western Reserve University's Jackson T. Wright Jr., MD, PhD, and Mahboob Rahman, MD, authors on NEJM study showing persistent positive effects of 120 target blood pressure*

19-May-2021 6:05 PM EDT, by [University Hospitals Cleveland Medical Center](#) [Contact Patient Services](#)

**Newswise — CLEVELAND** — Follow-up data from the landmark SPRINT study of the effect of high blood pressure on cardiovascular disease have confirmed that aggressive blood pressure management — lowering systolic blood pressure to less than 120 mm Hg -- dramatically reduces the risk of heart disease, stroke, and death from these diseases, as well as death from all causes, compared to lowering



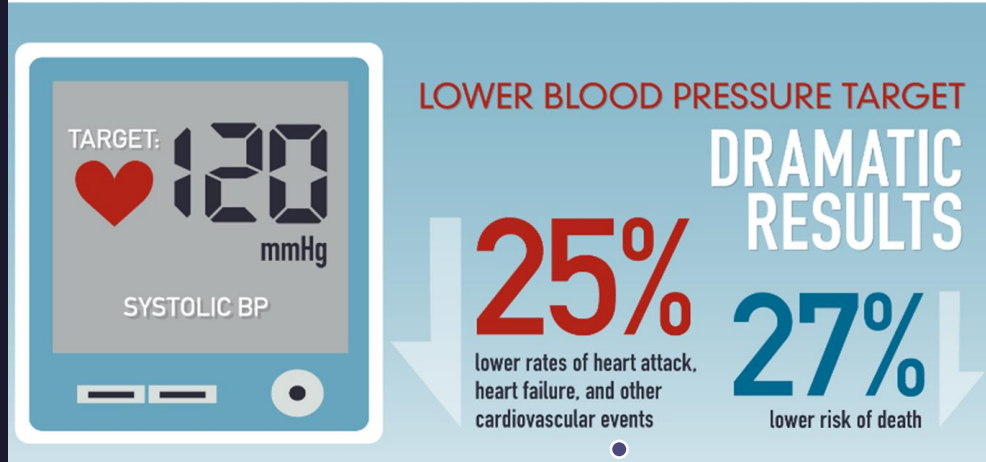
# SPRINT Trial

Racial/ethnic health disparities: Blacks and Hispanics have higher rates of uncontrolled blood pressure (BP), and Blacks are at greater risk of hypertension-related CVD morbidity and mortality. SPRINT had 30% Black and 11% Hispanic participants.

A Randomized Trial of Intensive versus Standard Blood-Pressure Control.

*N Engl J Med*, 2015;  
373:2103-2116. DOI:  
10.1056/NEJMoa1511939

Cited in **60 policy documents**, including US clinical guidelines (42), government ministries of health outside the USA, mostly Canada and the UK (12), inside the USA, including the CDC (1), and the World Bank (1) among others.



Supported by the Case Western Reserve University  
CTSC Clinical Research Units

‘2019 AHA/ACC Clinical Performance and Quality Measures for Adults With High Blood Pressure - A Report of the American College of Cardiology/American Heart Association Task Force on Performance Measures’ - *J Am Coll Cardiol*. 2019. November 26; 74(21): 2661–2706.  
doi:10.1016/j.jacc.2019.10.001

**\*IMPORTANT\***  
Having sufficient numbers of minorities in the trial meant the dramatic results were also statistically true for those minority groups.

# Mild Gestational Diabetes Trial

Hyperglycemia and Adverse  
Pregnancy Outcomes

**N Engl J Med 2008;**  
358:1991-2002

DOI:  
10.1056/NEJMoa0707943

Cited by **33 policy documents**, which included 6 governments outside the US, 4 from IGOs including the World Bank (1) and the WHO (3), **23 clinical guidelines** documents on both diabetes and gestational diabetes mellitus (GDM).

The WHO new 2013 guidelines **recommended glucose cut-off values for GDM are lower than those recommended by earlier guidelines**. Unlike earlier guidelines, they are based on the association of plasma glucose and adverse maternal and neonatal outcomes during pregnancy, at birth and immediately following it.

Diabetes Trial

CTSC CRUS

Policy citations

Clinical Guidelines

Human Health



Supported by the Case Western Reserve University **CTSC Clinical Research Units at MetroHealth** (Nurses performed the oral glucose tolerance tests.)

**World Health Organization.** (2013).  
Diagnostic criteria and classification of hyperglycaemia first detected in pregnancy.  
World Health Organization.  
<https://apps.who.int/iris/handle/10665/85975>

And

**24 Different Clinical Guidelines Documents** in PubMed Central

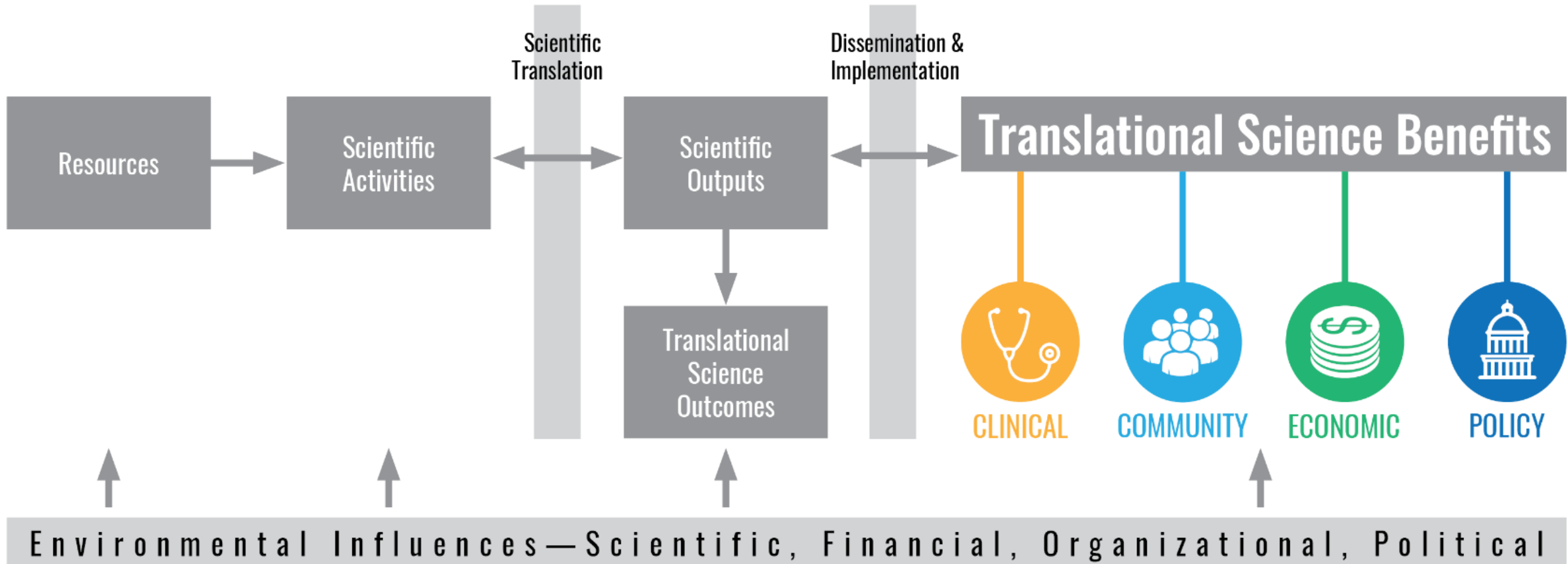
# Translational Science Benefits Model (TSBM)

The Translational Science Benefits Model: A New Framework for Assessing the Health and Societal Benefits of Clinical and Translational Sciences. [Clin Transl Sci \(2018\) 11, 77–84; doi:10.1111/cts.12495](#)



# Translational Science Benefits Model (TSBM)

## Conceptual Model



# Translational Science Benefits Model (TSBM)



**CLINICAL**



**COMMUNITY**



**ECONOMIC**



**POLICY**

## **Clinical & Medical Benefits**

(Procedures, clinical guidelines, tools, devices & products)

## **Community & Public Health Benefits**

(Health activities, care, programs and health promotion)

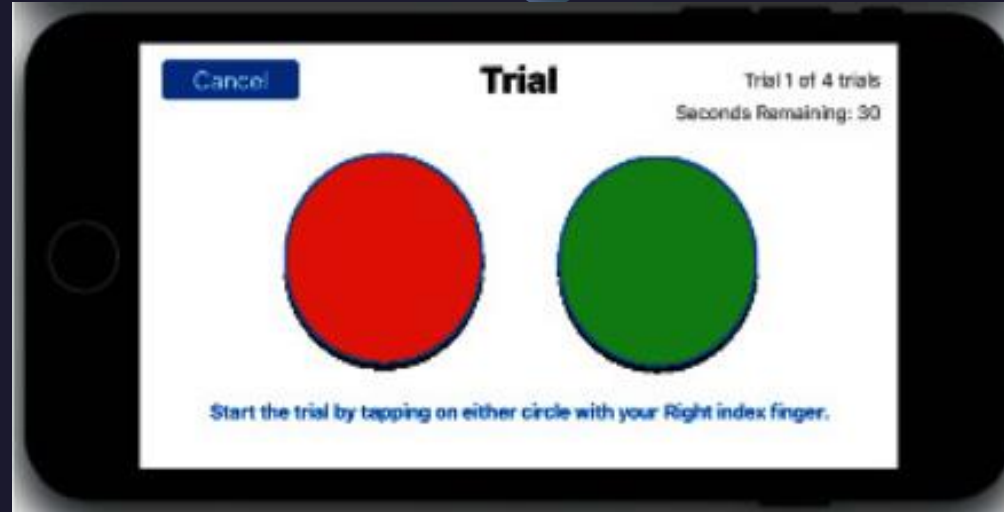
## **Economic Benefits** (Commercial products, financial savings and benefits)

## **Policy & Legislative Benefits** (Advisory activities, policies & legislation)



**Community  
& Public  
Health  
Benefits**

# KL2 Scholars' demonstrated TS benefits



Marisa McGinley – CONSUMER SOFTWARE

- **Smartphone tool was created to improve distance health care of multiple sclerosis patients**
- **Use of a Smartphone to Gather Parkinson's Disease Neurological Vital Signs during the COVID-19 Pandemic**



**Community  
& Public  
Health  
Benefits**

# KL2 Scholars' demonstrated TS benefits



## **Autism-Monitor**

Tracks the child's progress during the course of treatment with Autism Monitor to improve outcomes.



Thomas Frazier – HEALTH EDUCATION RESOURCES

- **Neurobehavioral Evaluation Tool for autism - created software (called Virtual IPM and Neuro IPM) that are used to administer the parent-report questionnaires and to administer webcam-collected patient performance measures**

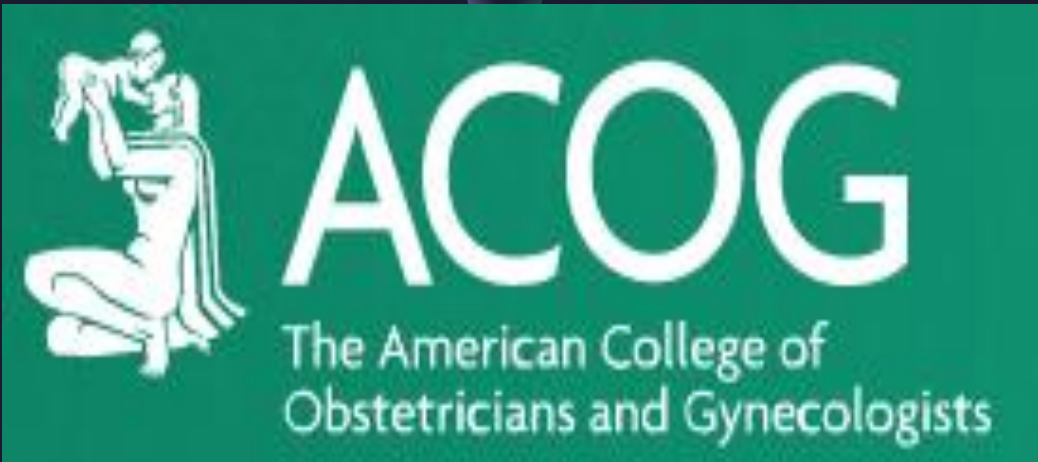
Thomas Frazier – US PATENT APPLICATION

- **ADAPTIVE PSYCHOLOGICAL ASSESSMENT TOOL -PATENT**



# KL2 Scholars' demonstrated TS benefits

Community  
& Public  
Health  
Benefits



Kavita Aurora – GUIDELINES

- **Sterilization of Women: Ethical Issues and Considerations by the American College of Obstetricians and Gynecologists' Committee on Ethics**

Kavita Aurora – COMMUNITY HEALTH SERVICES/HEALTH CARE ACCESSIBILITY

- **Basis for R01 on sterilization disparities**



# Summary



CTSA Program's Goal: Translate research findings into improved public health

- Evaluate health equity programming...will research follow? Unmeeting
- Evaluation research using TS case studies to uncover impact
- Researching policy documents uncovers major policy benefits
- Use the TSBM to begin to understand the benefits to society from research

Thank You

**Clara Pelfrey**

**[clara.pelfrey@case.edu](mailto:clara.pelfrey@case.edu)**

