



SYMPOSIUM

**BLACK
WO(MEN)
SPEAK**



Session 3

Pharma and Patient Advocacy
Collaboration: Strengthening
Best Practices

**BLACK
WO(MEN)
SPEAK**



SPEAKER

Maimah Karmo

The Advocate Perspective: The Truth
About Diversity and Clinical Trials

black-women-speak.org

**BLACK
WOMEN
SPEAK**



The Advocate Perspective: Diversity and Clinical Trials – From Admiring to Action

Maimah Karmo
CEO/President, Tigerlily Foundation

December 5, 2022

Tigerlily
Foundation
Beauty. Strength. Transformation.



We Must Move from Admiring the Problem to Ignite Action for Inclusive Clinical Trials

Barriers

- Distrust
- Logistics
- Access
- Fear
- Financial
- Employment issues
- Mental health
- Sexual health
- Co-morbidity issues
- Interests of people of childbearing age
- HCP is unaware of trials
- Stigma
- Patients diagnosed too late to qualify
- Rigid inclusion/exclusion criteria
- Health literacy
- Culturally / linguistically sensitive patient education about clinical trials
- Address patient concerns
- Patients' rights and risks
- Implicit/Explicit bias

Opportunities

- Build trusted partnerships with People before they are patients
- Embedded CBO, FBO engagement and trusted BIPOC providers
- Authentic patient engagement with all clinical trial stakeholders
- Community input for all phases of drug development
- Provide opportunities for learning more about clinical Trials, where the trials are located and the hope that they bring to people and communities
- Educate HCPs on clinical trials and their benefits
- Build Centers of Excellence at Community and Local Health Centers for diagnosis, biomarker testing and treatment
- Policy commitments and accountability





Partnering to Address Barriers

Partner with all Stakeholders , including Sponsors, Sites, Systems & Contract Research Organizations (CROs

Sponsor Engagements

Let us Lead. Engage patient every step of the way as leader/driver within the clinical trial ecosystem for BIPOC patients to support inclusive clinical trials (and research in general)

The Patient is the Customer. Design around our needs and deliver a memorable consumer experience (Think Nordstrom, Amazon, Walmart, Uber



CRO/Site Engagements

Accelerate inclusive best site practices and drive convenings of clinical trial site leaders in BIPOC communities, health systems and cancer centers working with CROs, sponsors, CBOS/FBOs, Oncology Nurse Organizations and other stakeholders

Stand up sites for sustainability and success

Deliberately address Barriers to clinical trials and SDOH with BIPOC patients. Implement solutions to address structural barriers in specific geo-targeted geo locations – 20 cities

Conference Presentation

Policy Change

Advocate for policy change – invest, pilot test, replicate on state and national level.





Tigerlily's Evolving Mission



To educate and empower women to be advocates for their health



To partner with communities, Sponsors and healthcare entities to reduce barriers and create a more inclusive clinical research ecosystem

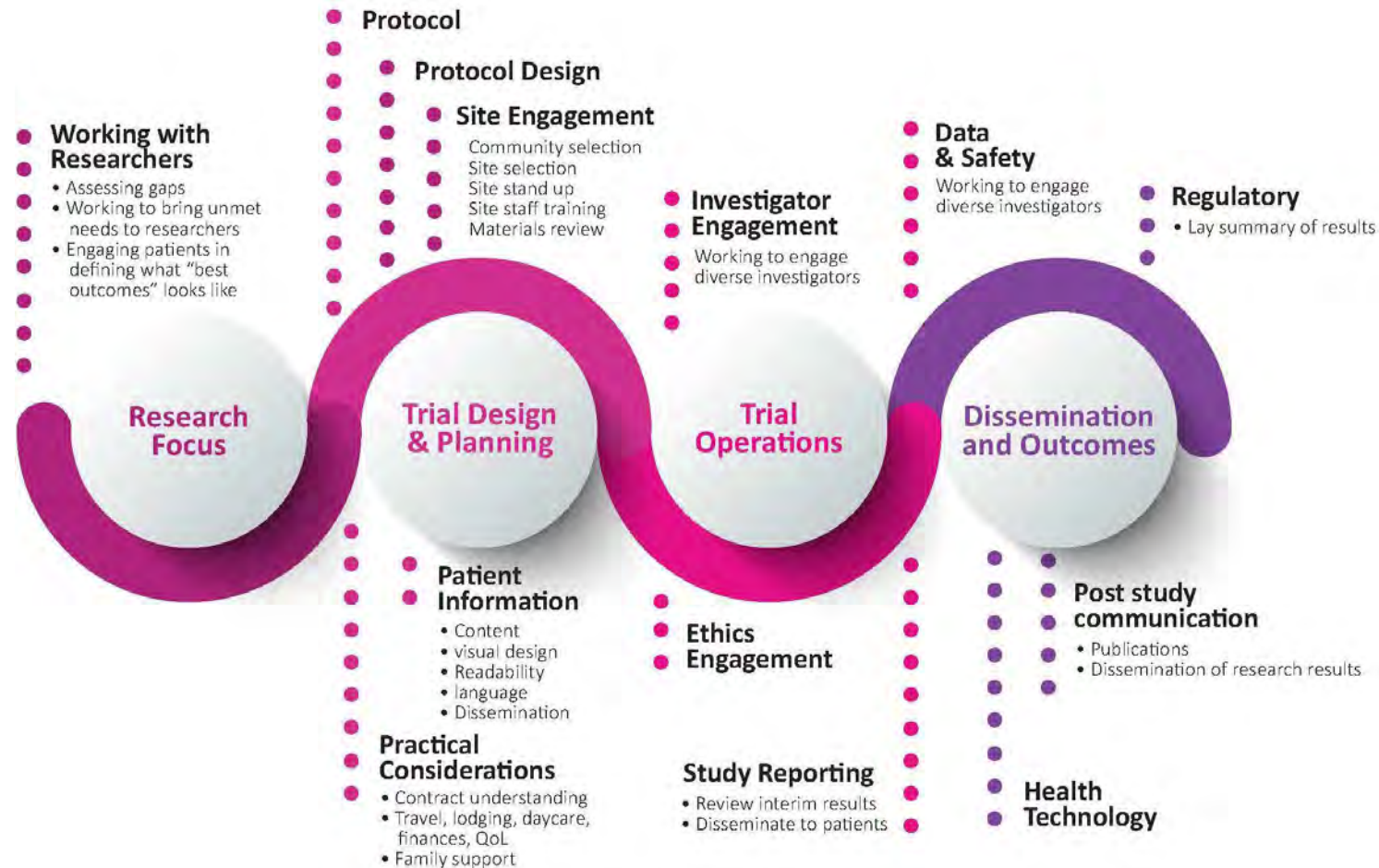


To lead and build a pragmatic advocacy framework that includes women in all communities to represent breast cancer and clinical trial participation



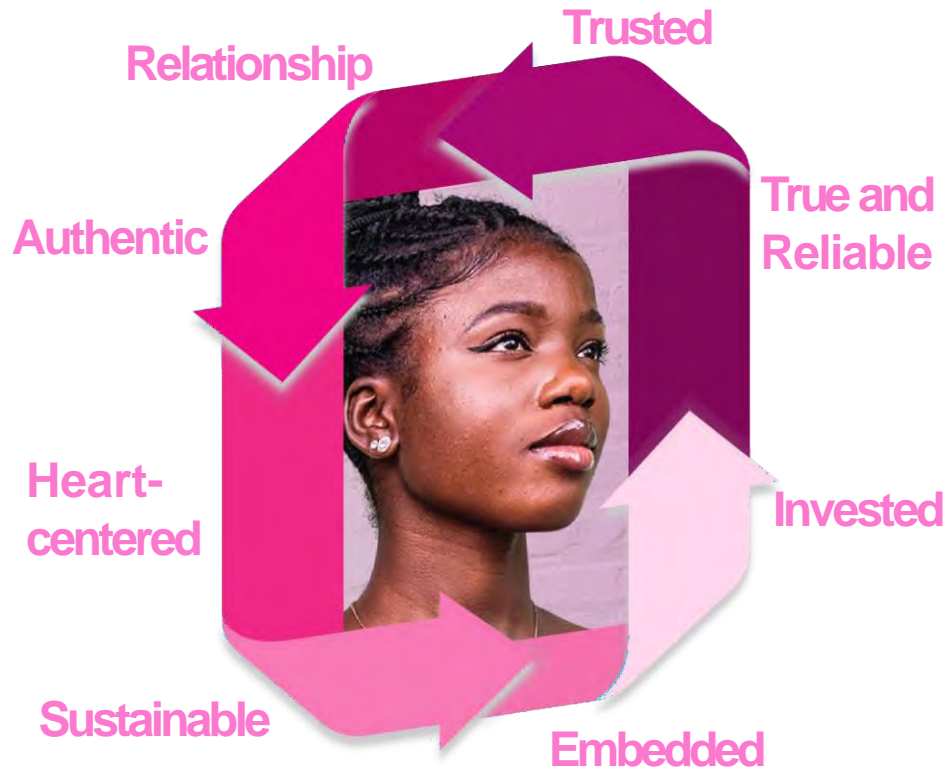


Tigerlily Foundation is working with stakeholders to engage patients at every intersection throughout the clinical trial journey





Tigerlily Foundation's Roar for Inclusive Clinical Trials



TLF Action for inclusive clinical trials by the numbers

28

Initiatives in Action

12

Initiatives in Active Planning





TLF's Roar for Inclusive Clinical Trials

Goal:

To dismantle barriers by driving transparency, brokering authentic partnerships, exposing and replicating best practices in the clinical trial ecosystem

To foster trust and increase access to clinical trials for those individuals most in need ---to ensure the representation of BIPOC communities in clinical trials.

Our Strategy has four major themes or pillars:



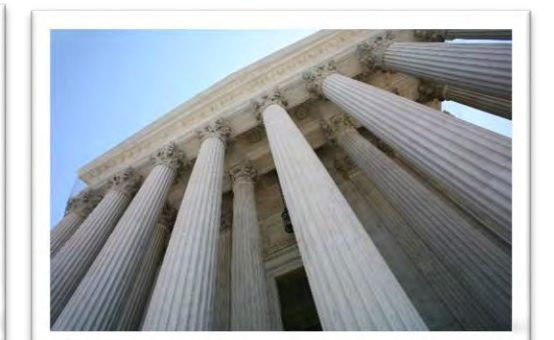
People - Multiply



Capacity Building



Multi-stakeholder Best Practices



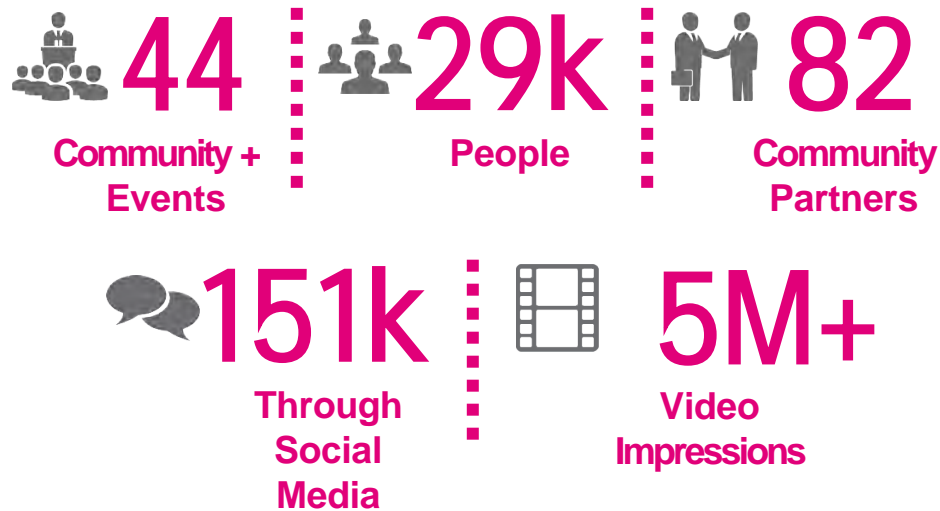
Policy



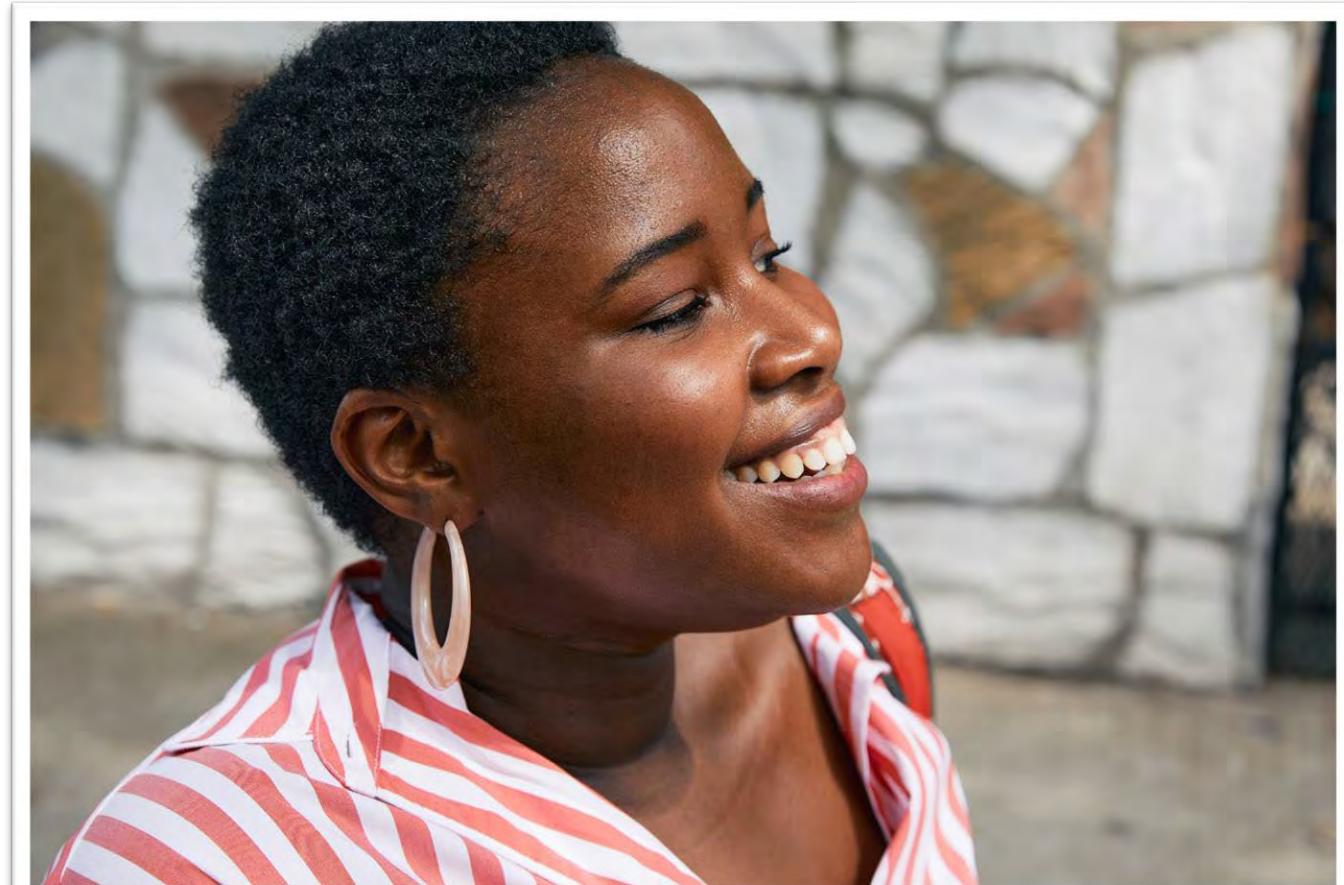


TLF Actions by Strategic Theme - “The Roar”

- Training Black patients/advocates in 20 cities on Clinical Trials
 - Healthcare is self care
- Trusted Angel engagement and navigation with BIPOC patients and caregivers with focus on 21 High risk metro areas/regions
- 5 Pilot Cities with ANGEL Leads



The People





TLF Actions by Strategic Theme- “The Roar”

Capacity Building





December 5, 2022, SABCS

TLF Actions by Strategic Theme— “The Roar”

The Multi-Stakeholder Best Practices

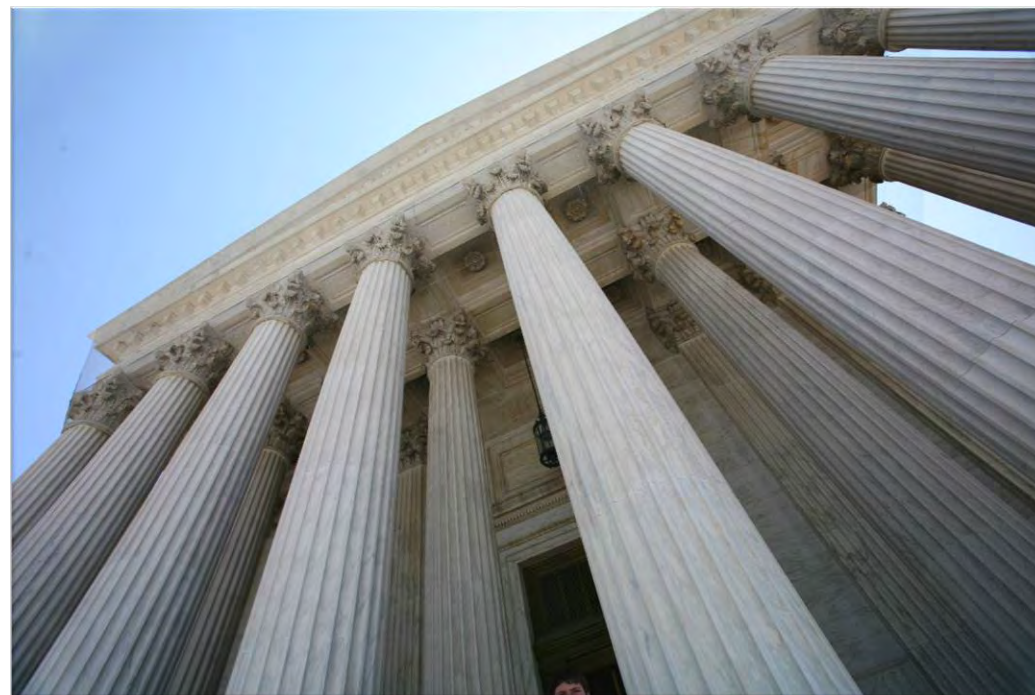




TLF Actions by Strategic Theme- “The Roar”

The Policy

- Worked with FDA on diversity plan inputs
- Working with sponsors on diversity plans
- Engage with NCI Cancer Center Outreach Leaders and nationalize alignment with FDA guidance
- The Diverse Act-Letter writing campaign with BIPOC patients supporting clinical trial and health equity initiatives
- Federal and State Level Policy Partnerships



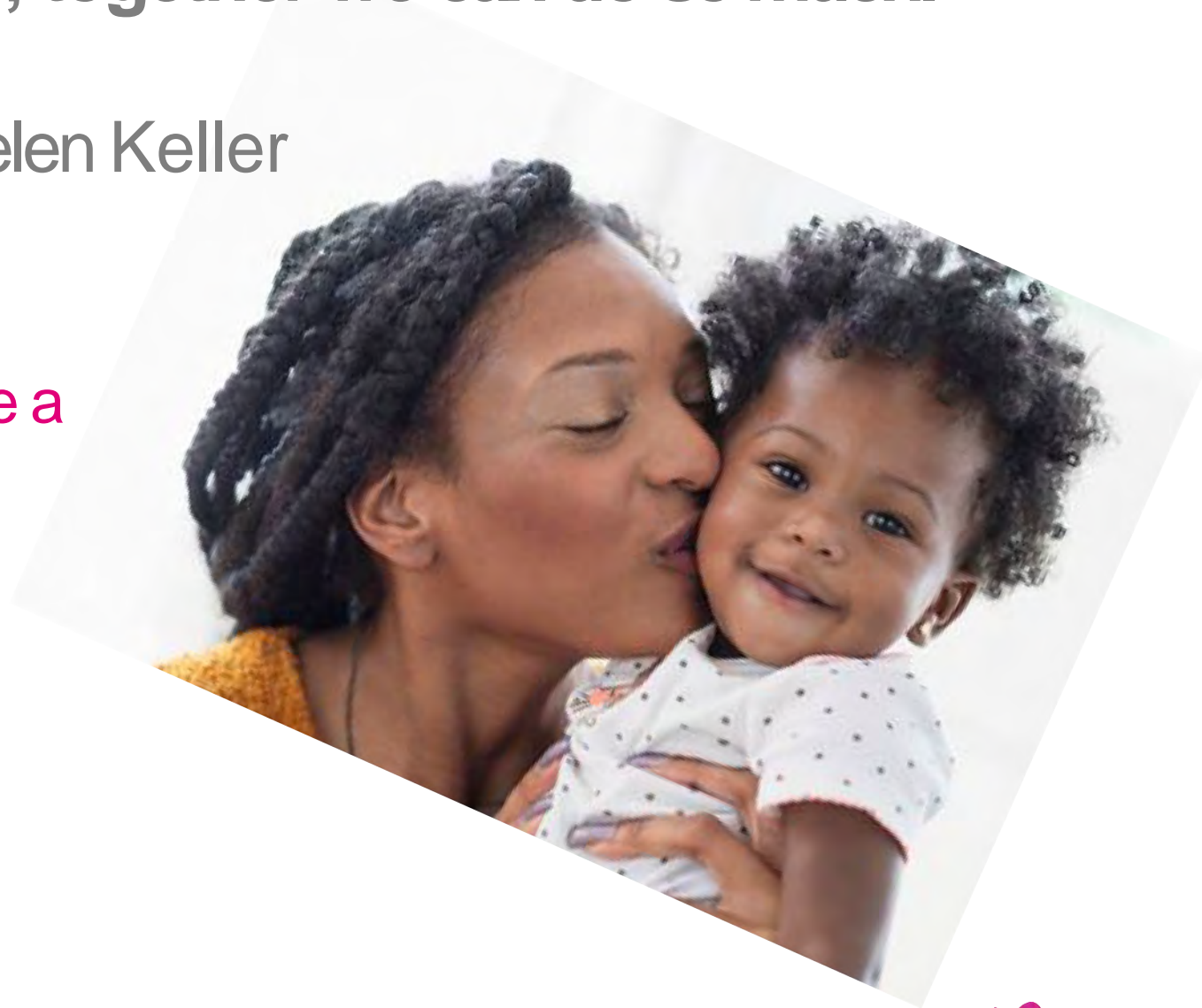


“Alone we can do so little; together we can do so much.”

- Helen Keller

We must move past the past and create a present that leads to a better future.

– Maimah Karmo





GET IN TOUCH WITH US



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