

Cultural adaptation of a Peer Clinical Trials Support program for the Hispanic/Latino cancer community in the U.S.: Focus Group Findings

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Cancer Support Community

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Disclosures



Erica Fortune, PhD:

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Maria Gonzalo, MS

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Peggy Rios, PhD:

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Kara Downey, MSW

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Our Mission

CSC uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care.

Our Reach

CSC and Gilda's Club centers as well as hospital partnerships in the U.S. and around the world.



**CANCER SUPPORT
COMMUNITY**
COMMUNITY IS STRONGER THAN CANCER



**GILDA'S
CLUB**

NATIONAL

CSC ARIZONA
CSC SOUTH BAY
CSC GREATER SAN GABRIEL VALLEY
CSC LOS ANGELES
CSC CALIFORNIA CENTRAL COAST
CSC SAN FRANCISCO BAY AREA
CSC VALLEY/VENTURA/SANTA BARBARA
CSC SW COLORADO
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CSC WASHINGTON D.C.
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CSC ATLANTA
GC CHICAGO
CSC INDIANA
GC QUAD CITIES
GC KENTUCKIANA
CSC MASSACHUSETTS
CSC GREATER ANN ARBOR
GC GRAND RAPIDS
GC METRO DETROIT
GC MINNESOTA
CSC GREATER ST. LOUIS
GC KANSAS CITY
CSC MONTANA

CSC NEW JERSEY
CSC ROCHESTER AT GILDA'S CLUB
CSC GREATER NY & CT AT GILDA'S CLUB
CSC GREATER CINCINNATI-NORTHERN KENTUCKY
CSC CENTRAL OHIO
CSC GREATER LEHIGH VALLEY
CSC GREATER PHILADELPHIA
GC MIDDLE TENNESSEE
CSC EAST TENNESSEE
CSC NORTH TEXAS
GC MADISON

HEALTH CARE PARTNERS

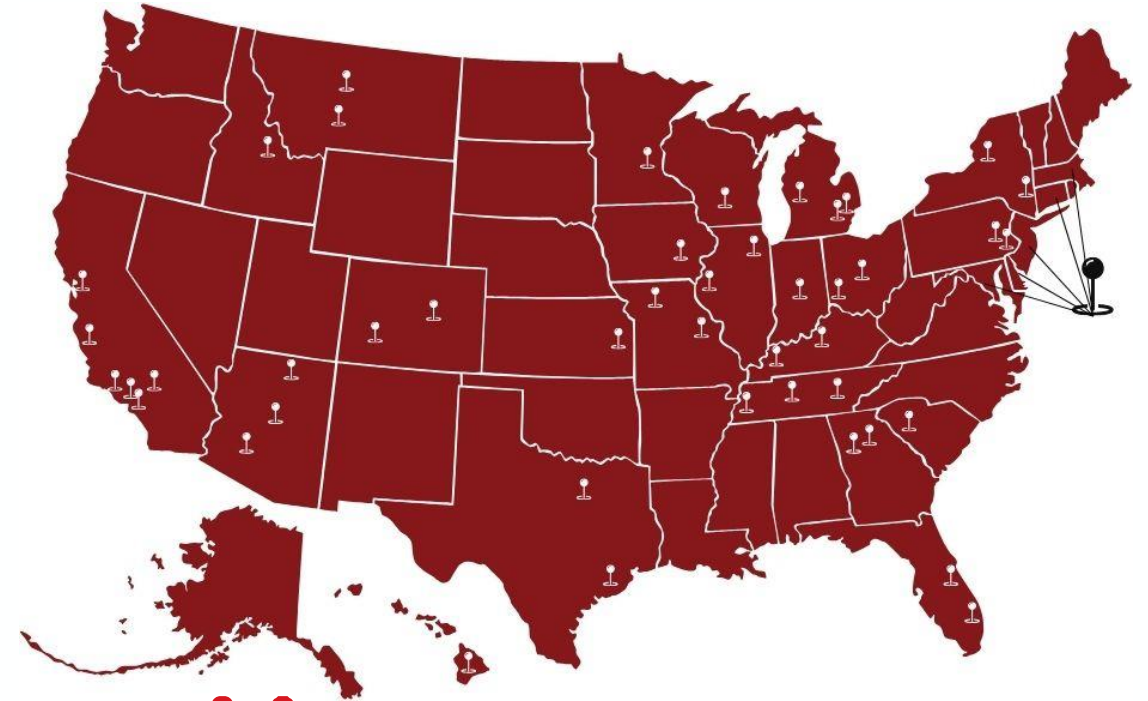
CSC AT TUBA CITY REGIONAL HEALTH CARE
CSC AT ROCKY MOUNTAIN CANCER CENTERS
CSC AT WHITMAN-WALKER HEALTH
CSC AT KONA COMMUNITY HOSPITAL
CSC AT MOSAIC LIFE CARE
CSC AT HOLY NAME MEDICAL CENTER
CSC AT IFHC (INDIAN FAMILY HEALTH CLINIC)
CSC AT PRISMA HEALTH CANCER INSTITUTE
CSC AT BRECKINRIDGE HEALTH, INC.
CSC AT MEMORIAL HERMANN
GC AT METHODIST CANCER INSTITUTE

INTERNATIONAL

GC GREATER TORONTO
GC SIMCOE MUSKOKA
CSC BAGHDAD
CSC JAPAN
TWC TEL-AVIV

UNIVERSITY LOCATIONS

CSC AT UNIVERSITY OF GEORGIA
CSC AT NORTHERN ARIZONA UNIVERSITY
GC AT ST. AMBROSE UNIVERSITY
CSC AT MONTANA STATE UNIVERSITY



HUB AND SPOKE MODEL:

The map shows all the US states CSC/GC have a physical hub.

Following a hub and spoke model, we are in 196 locations worldwide.

CSC Research and Training Institute

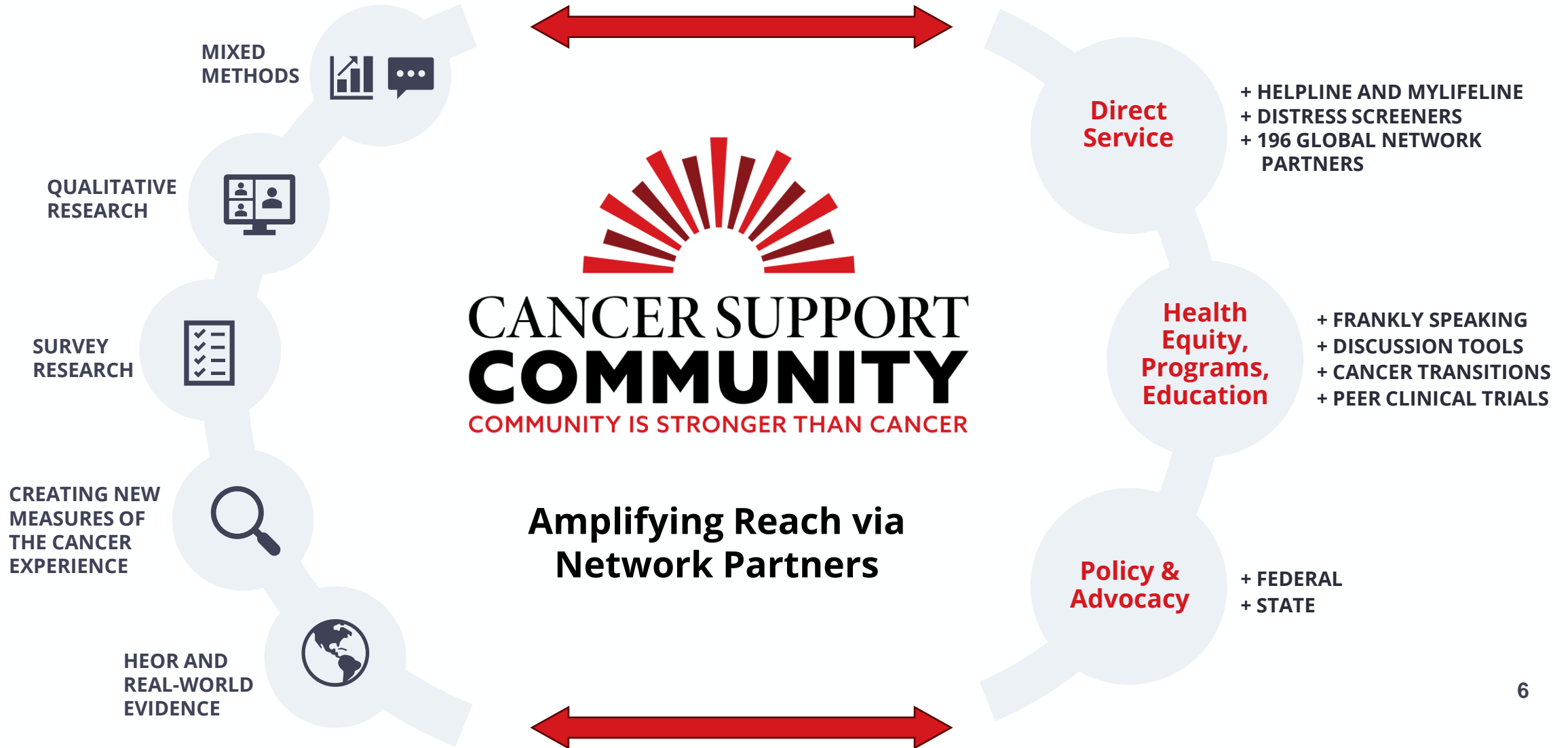
As experts in capturing unmet needs of cancer patients and caregivers, we evaluate patient, survivor, and caregiver voices through **psychosocial, behavioral, financial, survivorship,** and **health economics and outcomes research** using **real-world non-clinical data** to:

- Understand the cancer experience and impact
- Enhance cancer care
- Guide program development
- Influence health-related policy

The multidisciplinary team is comprised of researchers and program management professionals, including PhD level psychologists, sociologists, methodologists, and public health experts.



Research Capabilities



Learning Objectives

Objective 1

Analyze the unique barriers and facilitating factors that Hispanic/Latino patients encounter in navigating cancer care and clinical trial participation in the U.S., with a focus on how these challenges impact their involvement in clinical trials.

Objective 2

Evaluate the role of healthcare providers in addressing logistical, linguistic, and cultural barriers to improve clinical trial participation among Hispanic/Latino patients, including strategies to build trust and reduce healthcare disparities.

Background

Hispanic/Latino representation in Clinical Trials




- This study aims to understand the **challenges that Hispanic/Latino (H/L) patients in the U.S. face participating in cancer clinical trials (CCTs).**
- H/L patients remain underrepresented in CCTs, comprising **only 2-4% of CCT participants** (Espinoza-Gutarra et al., 2022), although they represent 20% of the U.S. population.

We sought to:

Following the success of a similar PCT for the Black/African American community, we seek to adapt the PCT program for the H/L community.

Peer Clinical Trials Program


Current Program



Talk With Someone Who Gets It

Get matched with a **black cancer patient or survivor** to talk about their clinical trial experience.

The support you need to understand cancer clinical trials.



Scan the QR code or call **1-888-292-5162 to enroll for free.**

Participants must be Black/African American cancer patients or survivors, 18 years of age or older.

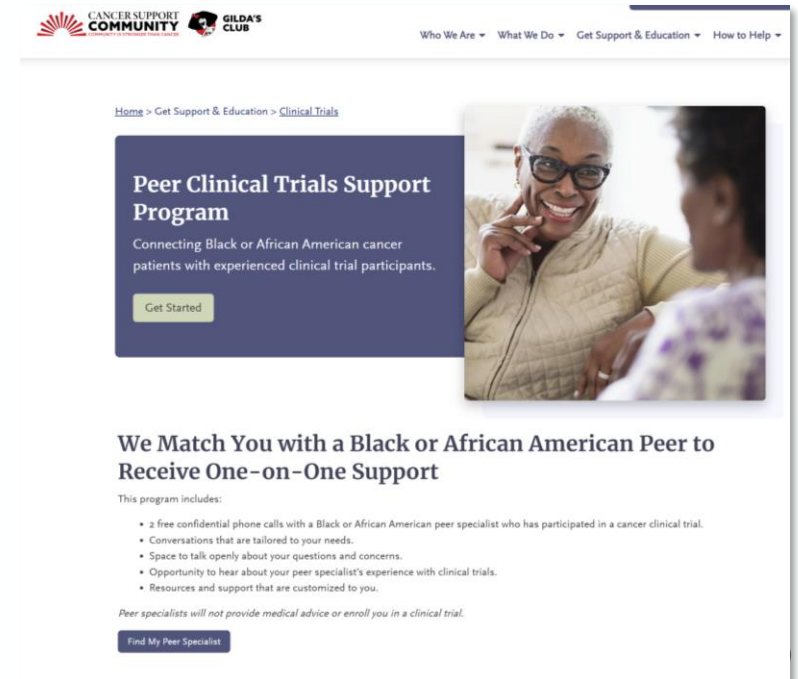
YOU'LL RECEIVE:

- ✓ One-on-one practical and emotional support.
- ✓ Help with how to talk to your healthcare team about clinical trials.
- ✓ Education and community resources.
- ✓ A safe space to talk freely.

The program aims to match patients with peers who can provide them with one-on-one practical and emotional support, via phone calls, as a **trusted messenger** who has gone through a similar experience.

During development, program acceptability and effectiveness were assessed with a focus on changes in clinical trials:

- Knowledge
- Perceptions
- Communication
- Likelihood of enrollment




Home > Get Support & Education > Clinical Trials

Peer Clinical Trials Support Program

Connecting Black or African American cancer patients with experienced clinical trial participants.

[Get Started](#)



We Match You with a Black or African American Peer to Receive One-on-One Support

This program includes:

- 2 free confidential phone calls with a Black or African American peer specialist who has participated in a cancer clinical trial.
- Conversations that are tailored to your needs.
- Space to talk openly about your questions and concerns.
- Opportunity to hear about your peer specialist's experience with clinical trials.
- Resources and support that are customized to you.

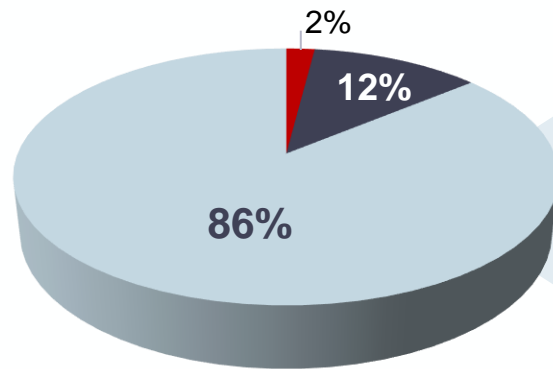
Peer specialists will not provide medical advice or enroll you in a clinical trial.

[Find My Peer Specialist](#)

PCT Black/African American

Program Outcomes and Learnings

How likely are you to enroll in a cancer clinical trial if offered the opportunity after participating in this program?



After the program, most people indicated they were **somewhat likely (31%)** or **extremely likely (54%)** to participate in a clinical trial.

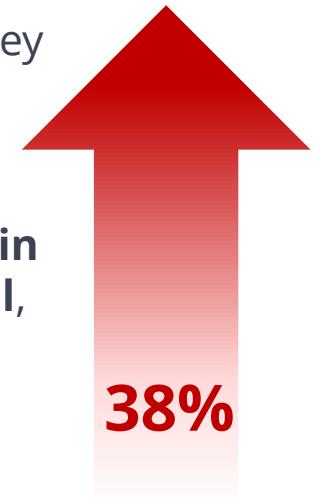
■ Unlikely ■ Neither Likely nor Unlikely ■ Likely

	BL	FU	Sig
I don't trust the medical establishment.	15%	10%	
I fear I will be used as a "guinea pig" for research.	14%	3%	<.05
Clinical trials are unsafe.	2%	1%	
There are no benefits to participating in a clinical trial.	3%	0%	
Confidentiality is respected for clinical trial participants.	88%	90%	

% shown for those who somewhat or strongly agree with statement; sig for paired sample t-test (N=89)

Key Learnings:

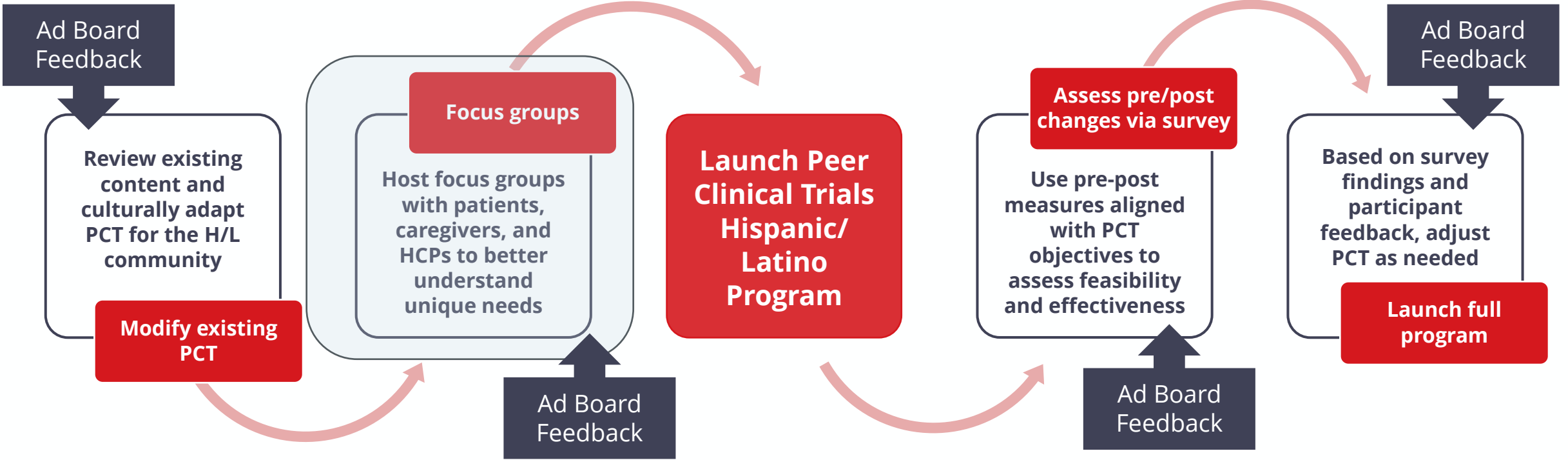
- 94% would recommend the program to others
- Participants reported an **increase in clinical trial knowledge**, from 43% at baseline (*moderately, fairly, or very knowledgeable*) to 98% at follow-up
- 64% indicated that they had **spoken to a member of their healthcare team about participating in a cancer clinical trial**, compared to 26% at baseline ($p < .001$)



Adaptation Methods & Results

Cultural Adaptation

Adapt program for Hispanic/Latino Communities



Methods

Current Phase: Focus Groups

- **Two focus groups** were conducted to assess barriers and facilitators to clinical trial participation by a H/L qualitative methodologist:
 - **Focus Group 1:** Facilitated in Spanish with Spanish-speaking H/L patients (n=4), caregivers (n=1), or both (n=3), which included 4 women and 3 men (ages 30-72), reporting cancer diagnoses of prostate, breast, ovarian, sarcoma, peritoneal, and leukemia.
 - **Focus Group 2:** Facilitated in English with H/L-serving healthcare providers (3 oncology social workers; 2 oncology nurses), 3 of which identified as Hispanic and/or Latino/a/x

Thematic analysis identified shared experiences and perceptions among the focus group participants.

Patient and Caregiver Results

Barriers and Facilitators to participation



- Most patients (**6/7**) had **little knowledge of CCTs** and faced significant barriers to participation.
- Commonly cited barriers included:
 - **logistical and financial challenges** (transportation, cost of care, work disruptions)
 - **emotional challenges** (fear, confusion)

*"I think the one that weighs most heavily is **uncertainty**. The fear of what could happen."*

– Prostate cancer survivor

*"... such as fear of side effects of new treatments or of receiving a **placebo**."*

– Breast cancer survivor

*"...at the beginning of the year it was very difficult for us because... we had to **pay the deductible**. You ... pay the full price of the drugs and they are very expensive. For the transplant...one that alone costs **\$600 a day**"*

- Leukemia survivor

*"I say at work I have to miss once a week and they say '**no look we need you every day**'"*

–Sarcoma survivor

Patient and Caregiver Results

Barriers and Facilitators to participation



- Avoiding other **undesirable treatments** or other treatments being ineffective

*“Well, I am currently in clinical studies...but initially because the other results other methods chemotherapy radiotherapy and surgery **were not as effective**. So that was the other option that was presented at that moment“*

–Sarcoma survivor

- Accessing **innovative care, contributing to science, and giving back to community** motivated participation

*When they offered it to me, I thought it is an **opportunity to help other people**, other women who are also going through the same thing. If I can help save the lives of other people, why not?“*

- Breast cancer survivor

Patients and their families wanted to learn about CCTs from Spanish-Speaking providers

Healthcare Provider Results

Barriers and Facilitators to participation

- All healthcare providers identified **access to care, language barriers, and financial toxicity** as primary obstacles for H/L patients, along with **logistical challenges** and **medical mistrust**.
- Providers also faced challenges facilitating H/L CCT participation, namely **heavy caseloads, lack of resources, existing bias, and cultural competency**.

*"The Protocols are so rigid, rightly because they need to get the information. But, I feel like it **discourages a lot of patients**, too, if they feel like they have to undergo a lot of testing that they don't feel is needed if they just go through standard treatment."*

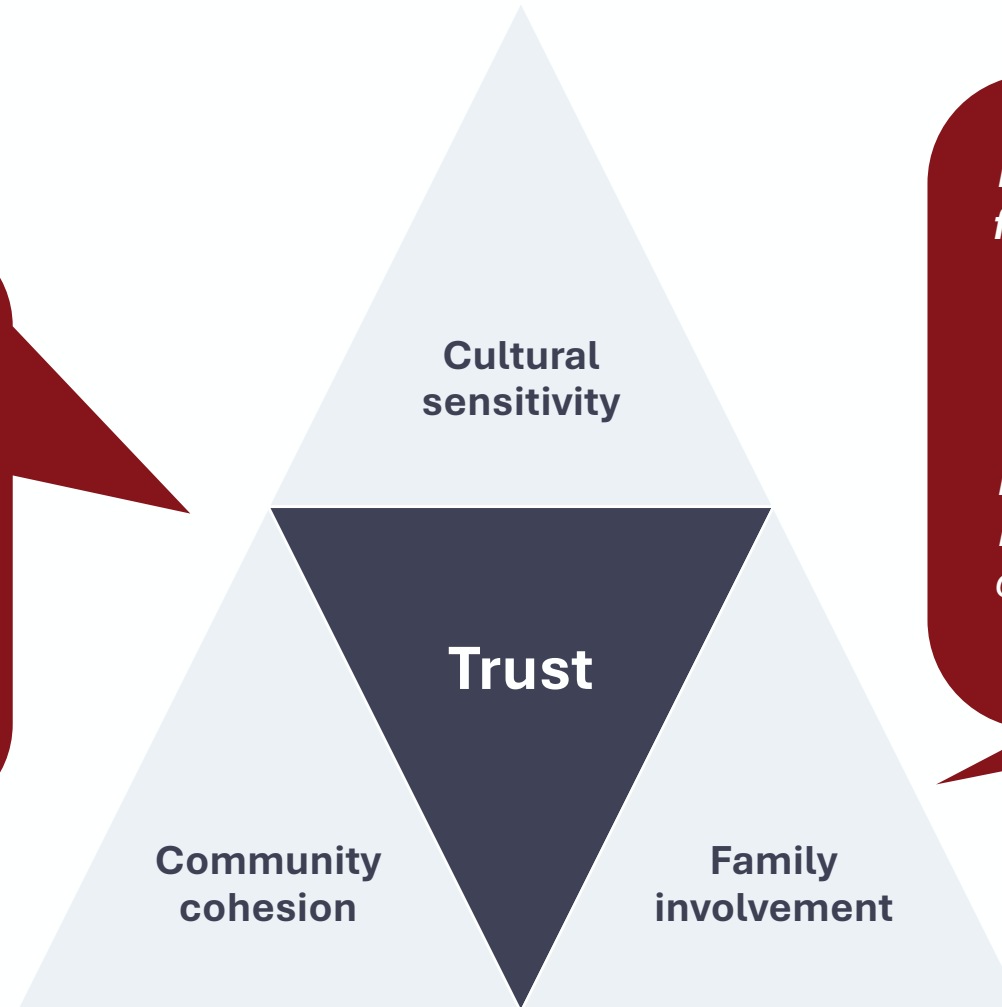
*"There's just not enough time. **Case management is significantly time-consuming**. There are so many calls involved. Time for us is a huge barrier especially when caseloads are exceptionally high. And so... it hinders your ability to show up consistently, which, again, would hinder your ability to appear or feel reliable to the patient and is going to impact the rapport that you have with them."*

*"It is important to do the internal work as a provider of what comes up for you when you meet... let me read a little bit about **what is the culture healthcare wise**."*

Healthcare Provider Results

Barriers and Facilitators to participation

*"There's cohesion in their communication. They share 'I found out about this resource, you know, this law change, and this is how it's going to affect us.' The way Hispanic people within their communities **communicate with each other** is just so beautiful and so remarkable to just have experienced." - OSW*



*"This is why you have a **relationship with the whole family**, not just the parents of the kids... they do rely on family members for encouragement, for maybe advice. When you have that relationship with all of them... it's up to me and some of the other parts of my team to talk to the family and help them understand" - OSW*

Conclusion

Supporting the H/L Community

Provider and System-Level Initiatives

- Provide resources to alleviate the financial burden and logistical challenges of cancer care.
 - Expand fair access to high-quality cancer care by addressing health literacy, language barriers, and provider bias.
- **Foster trust** within the Hispanic/Latino community through dedicated initiatives.
 - **Facilitate meaningful and genuine connections** among individuals diagnosed with cancer and survivors.
 - Develop a variety of support options, particularly those that are **culturally and linguistically aligned**, for individuals facing cancer and their caregivers.

Conclusions and Next Steps

Current Learnings and PCT H/L Program Launch

- To support H/L patients and caregivers in CCT participation, the program should address the **structural barriers to care**, such as providing **financial navigation and logistical support**, and meet culturally-specific needs, such as language-concordance and **including families and building trust**.
- The current findings will be used to **adapt the PCT program for pilot testing with H/L patients**. Next steps will include:
 - Finalizing program materials and operations with support from the ad board, hiring and training peer mentors in the next two months, and launching the full program in the summer (June/July)
 - Evaluating program acceptability and effectiveness through pre-post assessments

Thank you

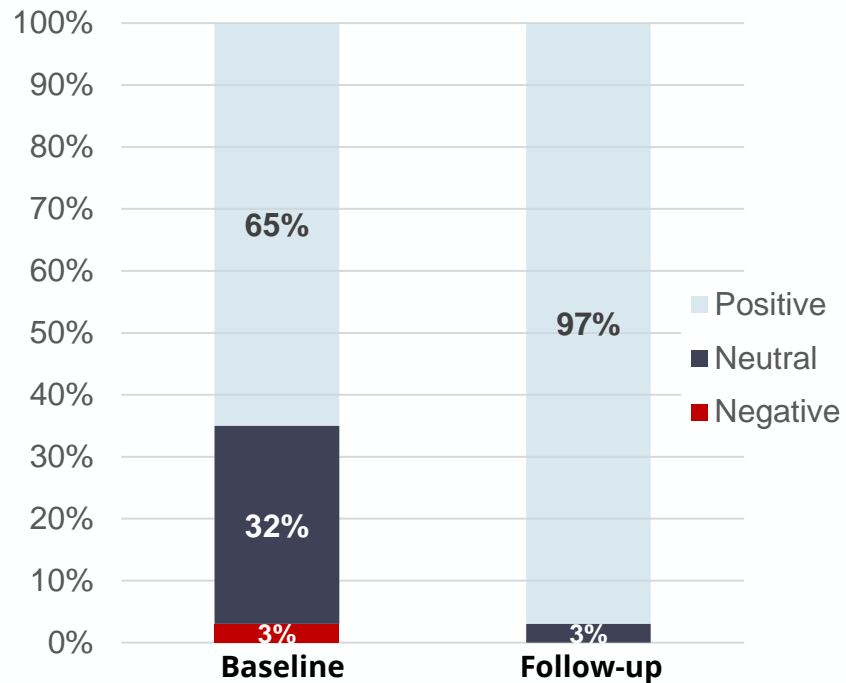
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Additional Slides

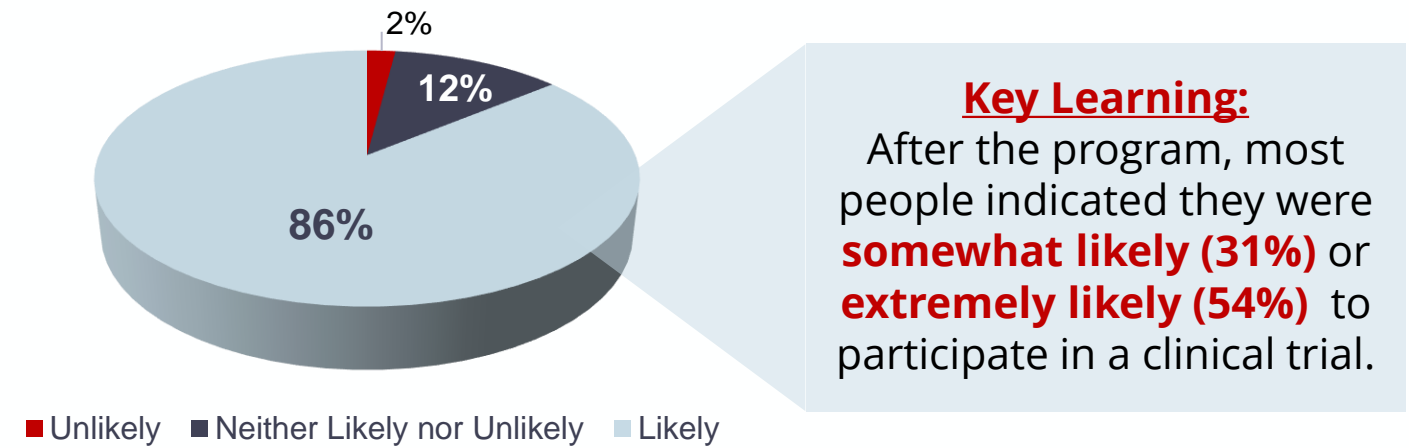
PCC Black/African American

What is your overall perception of clinical trials?



Key Learnings: There was a significant improvement in perceptions of clinical trials. At Follow-up, **0% had a negative perception** and **97% had a positive perception** of clinical trials.

How likely are you to enroll in a cancer clinical trial if offered the opportunity after participating in this program?

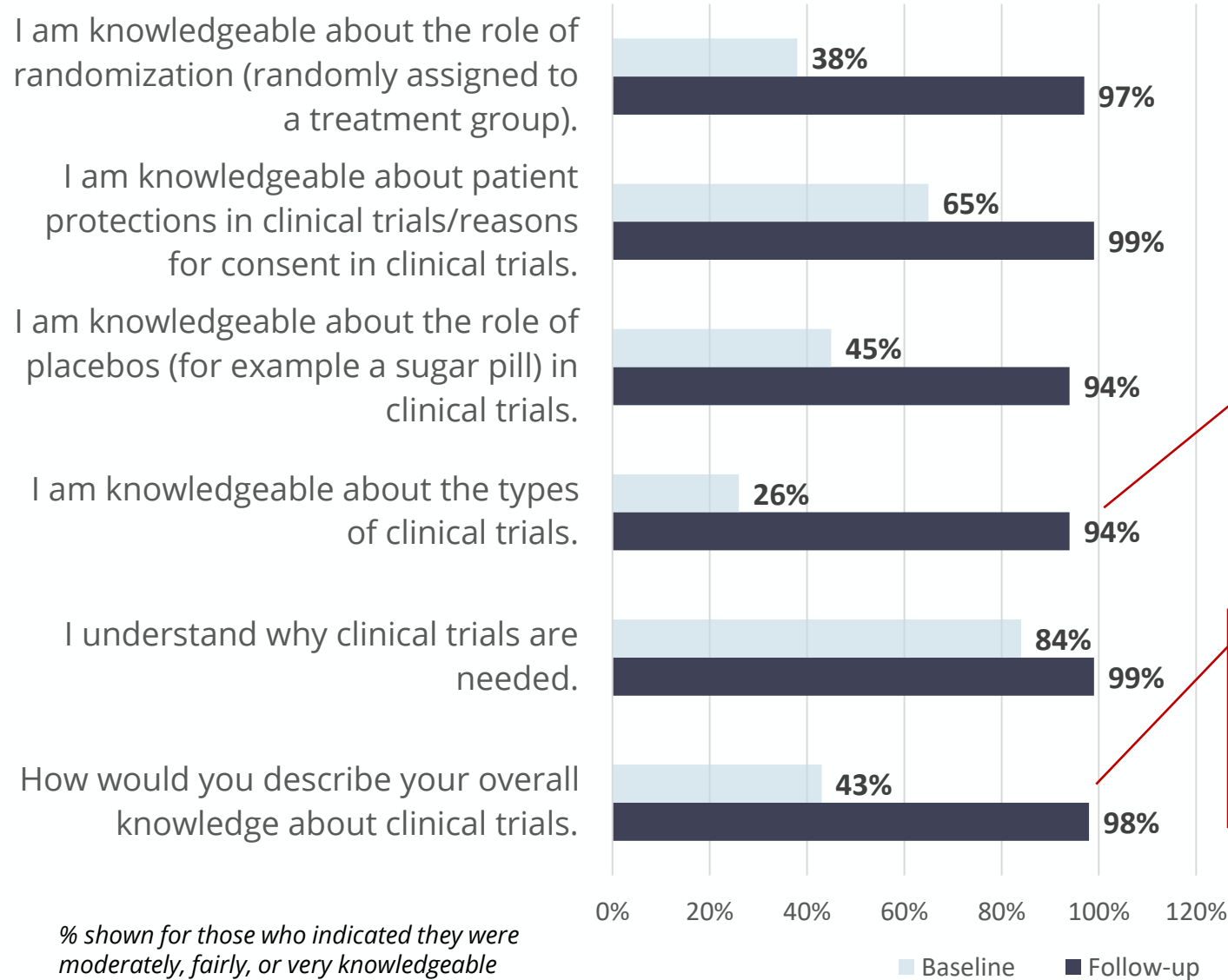


Key Learning: After the program, most people indicated they were **somewhat likely (31%)** or **extremely likely (54%)** to participate in a clinical trial.

Change in perceptions between baseline and follow-up

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I fear I will be used as a "guinea pig" for research.	14%	3%	<.05
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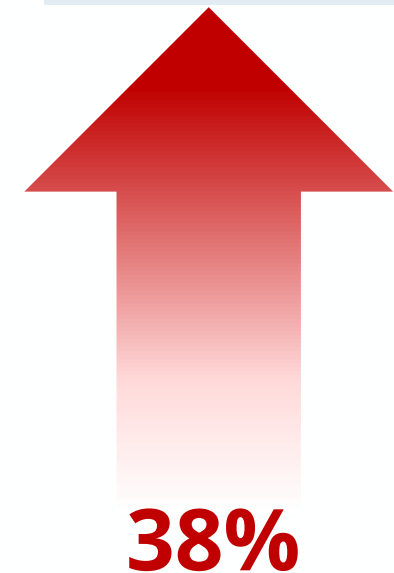
Key Learnings:

After completing the peer-mentor program, participants reported an **increase in clinical trial knowledge.**

The greatest increase (68%) occurred for knowledge about the **types of clinical trials.**

Overall clinical trial knowledge increased from 43% at baseline to 98% at follow-up.

At follow-up, 64% of respondents indicated that they had **spoken to a member of their healthcare team about participating in a cancer clinical trial**, compared to 26% at baseline ($p < .001$).



Overarching Findings

Barriers and Facilitators to Participation

