



***Advocating Alongside and
Not Just About.***
**Community Outreach &
Engagement**

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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 Vision

Everyone impacted by cancer receives the support they want and need throughout their experience.

Our Reach

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



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
CSC DELAWARE
CSC WASHINGTON D.C.
GC SOUTH FLORIDA
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 ORLANDO HEALTH CANCER INSTITUTE
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

What We Do

Patient Services, Insight, and Advocacy

Delivering innovative support and educational programming, both in-person and online



Direct Services : Institute for Excellence in Psychosocial Care

- Create and disseminate new and innovative models of care
- Affiliate Network- 50 markets, 175 locations
- Helpline and MyLifeLine
- Programs and Education across the continuum

Policy & Advocacy: Cancer Policy Institute

Committed to ensuring:

- Access to comprehensive cancer care for all patients.
- Quality as a central theme.
- Research as a critical priority.

Research & Training: Research & Training Institute

- The first and only *Institute* in the U.S. dedicated to cancer psychosocial, behavioral, and survivorship research and training.
- Comprised of a multidisciplinary team of clinical and research professionals including PhD level clinical psychologists, epidemiologists, statisticians and anthropologists.





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Defining the Need



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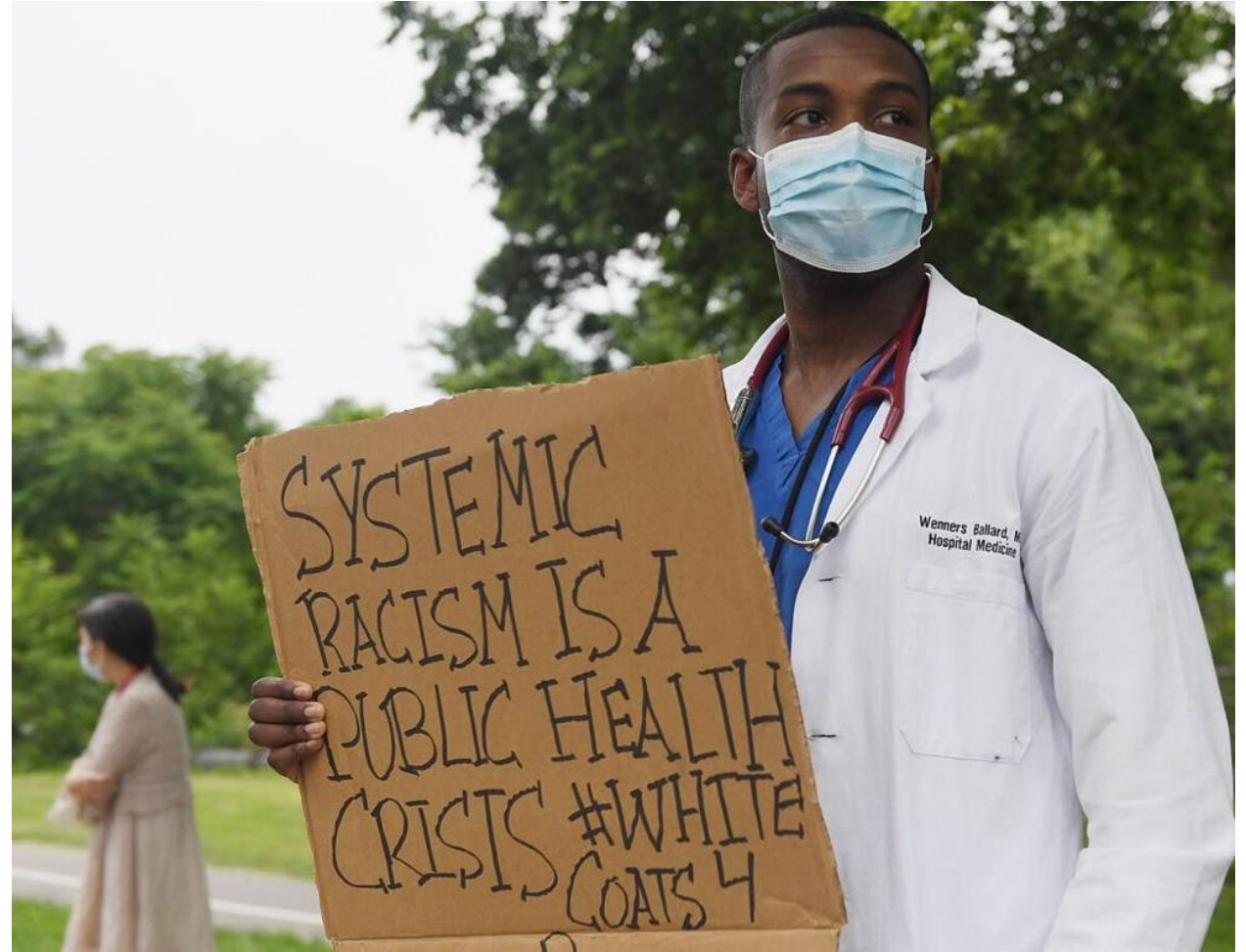
**HEALTH
EQUITY**
IN ACTION



The Need

Intentional efforts to gain community trust.

Mistrust remains high. Contemporary experiences, coupled with historical injustices, must be acknowledged for trust-building to begin.



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Connecting the Pieces

Mistrust

Acknowledge and Address

A **protective response** against the pervasive, interlocking structural inequalities that result in restricted access to resources, including housing, educational opportunities, employment, and healthcare, in addition to daily experiences of racism, stigma and discrimination.



Trust-Building Today



BACKGROUND

- Black patients make up 20% of people living with multiple myeloma, yet they represent only 6% of participants in clinical trials.
- Underrepresentation of Black patients in clinical trials can contribute to outcome disparities thereby negatively impacting health equity in cancer treatment and outcomes.

AIMS

- Findings will inform the development of programs aimed at increasing clinical trial participation in this population, including these Cancer Support Community education & support programs:
 - Frankly Speaking About Cancer (FSAC): Multiple Myeloma www.CancerSupportCommunity.org/Multiple-myeloma
 - FSAC Clinical Trials www.CancerSupportCommunity.org/ClinicalTrials
 - Peer Clinical Trial Support www.CancerSupportCommunity.org/peer-clinical-trials-support-program

METHODS

- Online survey of Black Multiple Myeloma patients and their caregivers/care partners.
- Survey questions were informed by insights from prior focus groups with Black Multiple Myeloma patients and caregivers/care partners.

PARTICIPANTS

N = 195	Mean / n	SD / %
Age (years)	46.2	9.7
Race and Ethnicity		
Non-Hispanic Black/African American	186	95%
Hispanic Black/African American	9	5%
Men	121	62%
Role		
Diagnosed with Multiple Myeloma	94	48%
Caring for Patient with Multiple Myeloma	101	52%
Household Income		
\$0-\$24,999	16	8%
\$25,000-\$49,999	71	38%
\$50,000-\$74,999	57	30%
\$75,000-\$94,999	21	11%
\$100,000+	24	13%

CONCLUSIONS/MAIN FINDINGS

- Top Patient & Caregiver Perceptions of Clinical Trials:**
 - Fear of side effects
 - Discomfort with random assignment
 - Only being willing to participate if the patient's current doctor recommended it
- Top Facilitators for Increasing Enrollment in Clinical Trials:**
 - Understanding potential side effects of the trial's treatment
 - A member of the patient's healthcare team speaks to them about cancer clinical trials
 - Compensation for transportation, childcare, or time off work to participate in the clinical trial

Our study highlights that Black and African American multiple myeloma patients and caregivers value multifactorial efforts to increase clinical trial participation: logistical and financial interventions, patient/provider communication, and culturally sensitive support and education programs.

RESULTS

Most Common Patient & Caregiver Perceptions of Clinical Trials

	Strongly Agree/Agree
1. I fear side effects might come with treatment in a clinical trial	63%
2. I am uncomfortable with being randomly assigned (in a process similar to a coin toss) to a treatment	56%
3. I would only participate in a clinical trial if my current doctor recommended it	50%
4. There are no clinical trials available in my community	47%
5. I would be unable to fulfill trial requirements due to the cost of non-healthcare expenses such as missing work due to additional appointments, transportation, or childcare	45%
6. My health insurance would not cover it	45%
7. I would be unable to fulfill trial requirements due to logistical barriers such as transportation or childcare	39%
8. I fear receiving a placebo (for example, a sugar pill) in a clinical trial	38%
9. I don't understand what clinical trials are	28%

RESULTS (Cont.)

Top Facilitators for Increasing Enrollment in Clinical Trials

	Strongly Agree/Agree
1. I understand potential side effects of the treatment being offered in the clinical trial	66%
2. A member of my healthcare team speaks to me about cancer clinical trials	65%
3. Compensation is offered for transportation, childcare, or time off work	62%
4. My family/community support my decision to participate in the clinical trial	61%
5. I receive detailed information explaining the study, the costs associated with participation, and what will be covered by the study	60%
6. I know whether or not I will get a placebo	60%
7. I understand the potential risks and benefits of participating in the clinical trial	60%
8. Money is offered for my participation	60%
9. I don't have to change treatment facilities to join the trial	58%
10. A friend or family member is participating in the same study	58%
11. I understand the treatment that I would potentially receive	57%
12. Hearing testimonials/reviews from other cancer patients that participated in the clinical trials	56%
13. The doctor/team conducting the research speaks the same language as I do	54%
14. I understand the research being conducted by the clinical trial	53%
15. I don't have to change doctors to join the trial	52%
16. The doctor/team conducting the research is the same race/ethnicity as me	47%
17. The doctor/team conducting the research is the same gender (sex) as me	45%

FUTURE DIRECTIONS FOR RESEARCH

- Need for more research among Black/African American population regarding clinical trials
- Need for longitudinal research in this area
- Need for research on ways to reduce barriers to clinical trial enrollment among Black/African American patients

ACKNOWLEDGMENTS

Support for this survey was provided by Amgen, bluebird bio, & GSK. The focus groups that informed the survey questions were supported by funding from Celgene.

Community Based Systems Dynamics:

Factors Fueling Medical Mistrust

Objectives & Aims:

Utilize a community-engaged research approach to:

1. involve communities in conceptualizing a system, how it works, what influences medical mistrust, and what is needed in the system to encourage trust.
2. include lived experiences of cancer survivors to identify areas of equity and inequity
3. inform practice and policy



Community Based Systems Dynamics:

Factors Fueling Medical Mistrust



The Informed and Empowered Patient

Access to information better equips a patient to have more control over decision.

Health care providers and advocates should spend more time improving access and accuracy.

Implement accountability structures outside of the training room.

Providers need additional training on incorporating accountability structures around diversity, equity, and inclusion.

Racially concordant care is very important to decreasing medical mistrust.

Culturally-Aware, Humble, and Inclusive Providers

Resource-Rich Community and Social Context

Marginalized communities are often resource deserts.

Partnering with local organizations, providing information, or providing community talks by HCPs who look like the community can be helpful.

Encourage policies that fund the training of more young people of color to enter oncology care.

Cancer care needs advocates in the provider-patient shared decision-making context.

Intentionally ensure that patients have an advocate onsite to help equip them to make decisions about their own health care.

Advocacy

Cancer Policy Institute (CPI)

Policy & Advocacy

The CPI brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policy making.



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Cancer Policy Institute

Grassroots Network

The Grassroots Network is a place where you make your voice heard at the local and national level to policymakers.

- Get up-to-date information on key issues that are important to patients with cancer and their loved ones.
- Be part of a network that interacts with Capitol Hill and other policy makers on issues important to cancer patients.
- Have your voice heard alongside other voices of patients with cancer and their loved ones.
- Participate in research being conducted at the Cancer Support Community.



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Research & Training Institute (RTI)



We elevate patient and caregiver voices through research to:

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



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Cancer Experience Registry

An online research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers.

Real World Value



Influence health care policy

CER data was used in discussions with congressional staff and press on preserving Medicare Part D's 6 protected classes in February

Leveraged during key discussions with congressional and regulatory leaders



Improve support services

CER data is used to support community grant submissions and secure funding for research and programming

Provides insights which help inform development of innovative patient/caregiver programs



Enhance cancer care

CER data led to the development of a brief and reliable adaptation of CancerSupportSource® (CSS), a comprehensive distress screening program used to address unmet needs and enhance well-being of patients and caregivers

Allyship

What can I do?

- **Speak up:** Break the silence
- **Take Responsibility:** Make privilege visible. Interrupt racism and microaggressions.
- **Speak truth to power:** Stand up for what's right
- **Speak your power for truth:** Use your power to debunk the lies and hold others accountable
- **Work collaboratively** with communities
- **Do the work!** Work through shame and guilt from a place of self-love



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The Peer Clinical Trials Support Program

Program Metrics: Patient Demographics + Clinical History

124 Baseline Participants

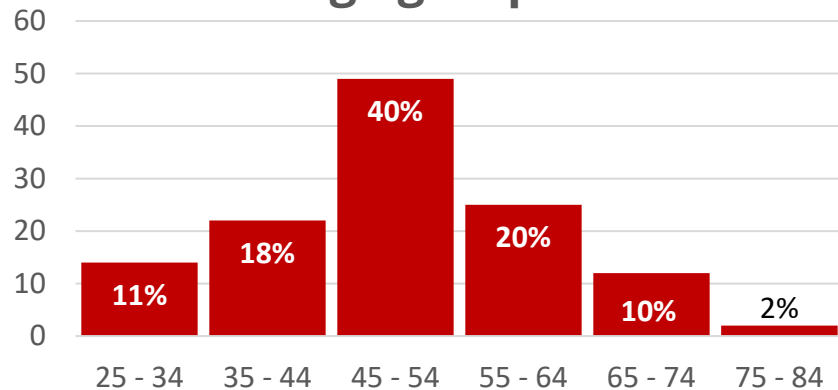
89 Follow-up Participants

89% women, 11% men

All Black/AA; 6% Hispanic

40% with 4-year, professional, or doctorate degree

Age group



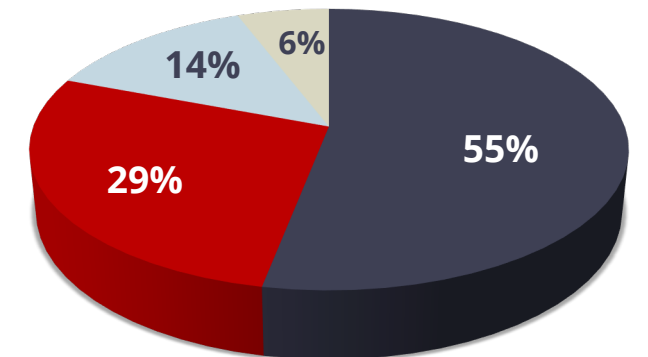
All values calculated from baseline sample (N=124)

Cancer Diagnosis	N	%
Breast	72	58%
Colorectal Cancer	8	6%
Multiple Myeloma	4	3%
Leukemia	5	4%
Lymphoma	5	4%
Lung Cancer	3	2%
Sarcoma	3	2%
Other*	23	19%

*Other cancers with <2% each included: endometrial/uterine, gastrointestinal stromal tumor, kidney, neuroendocrine tumor, ovarian, pancreatic, cervical, head and neck, prostate, stomach, among others.

82% cancer patient
17% cancer survivor
2% "previvor"

Cancer Status

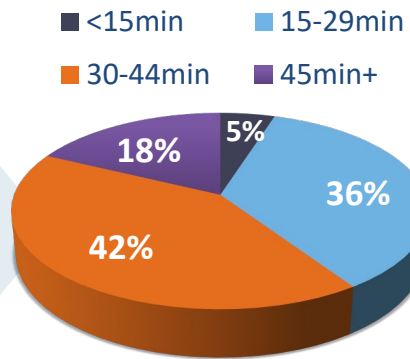


■ In treatment
 ■ Newly diagnosed
 ■ Post-treatment survivor
 ■ Unsure/Missing

Program Metrics: Initial and Follow-Up Call Data

Initial Call

113 people reached
 58% first attempt
 28% second attempt
 13% third attempt

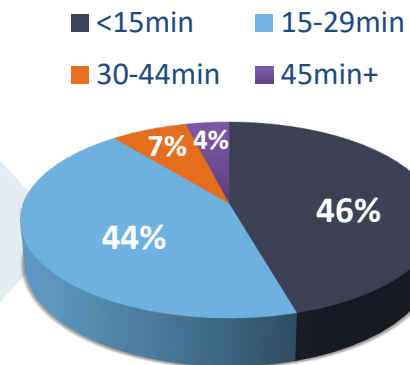


Average call length = **33min**

Average of **16 days** between initial and follow-up calls

Follow-Up Call

106 people reached
 68% first attempt
 19% second attempt
 14% third attempt



Average call length = **17min**

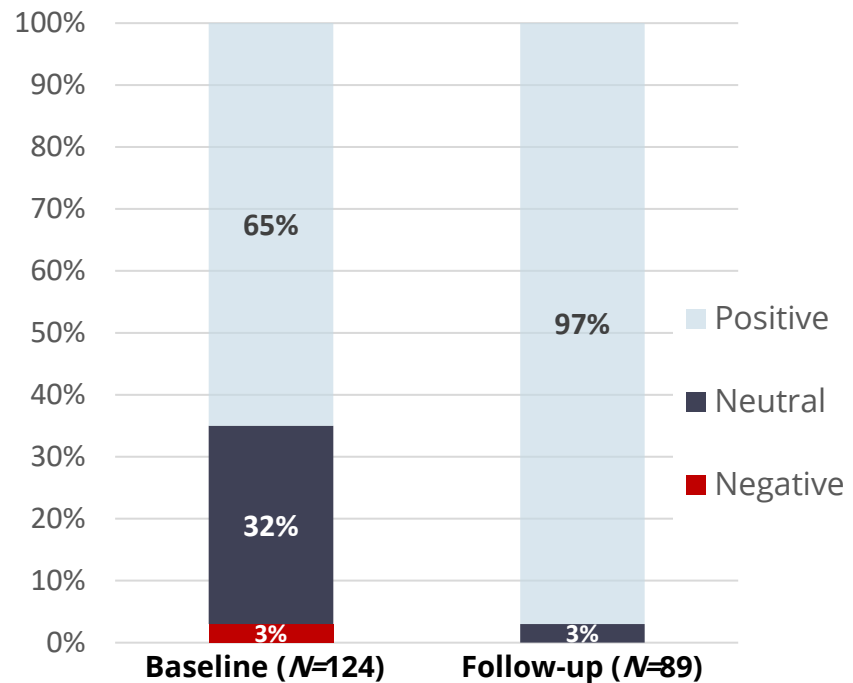
Topics discussed during call	Initial	Follow-Up
Clinical trial basics (what is a clinical trial, types of trials)	97 86%	26 24%
How clinical trials works (phases, guidelines)	62 55%	8 7%
Talking to a physician/healthcare team	64 57%	44 41%
How people are protected in clinical trials	60 53%	4 4%
How to find a clinical trial	54 48%	38 35%
Risks and benefits of clinical trials	52 46%	13 12%
Fears and concerns about clinical trials	43 38%	6 6%
Myths about clinical trials	29 26%	1 1%
What questions to ask about clinical trials	24 21%	12 11%
Financial and logistical concerns	23 20%	17 16%
Talking to family/friends	12 11%	9 8%



Key Learning: Clinical trial basics still discussed at follow-up, but focus shifted to **talking to physician or healthcare team about clinical trials** and **how to find clinical trials**

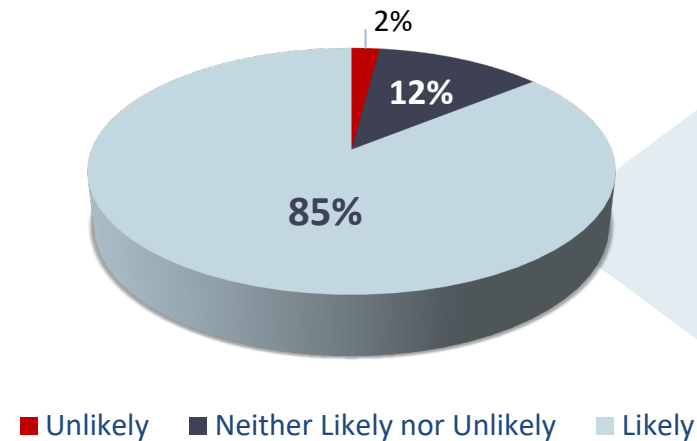
Program Metrics: Positive Clinical Trial Perceptions

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:

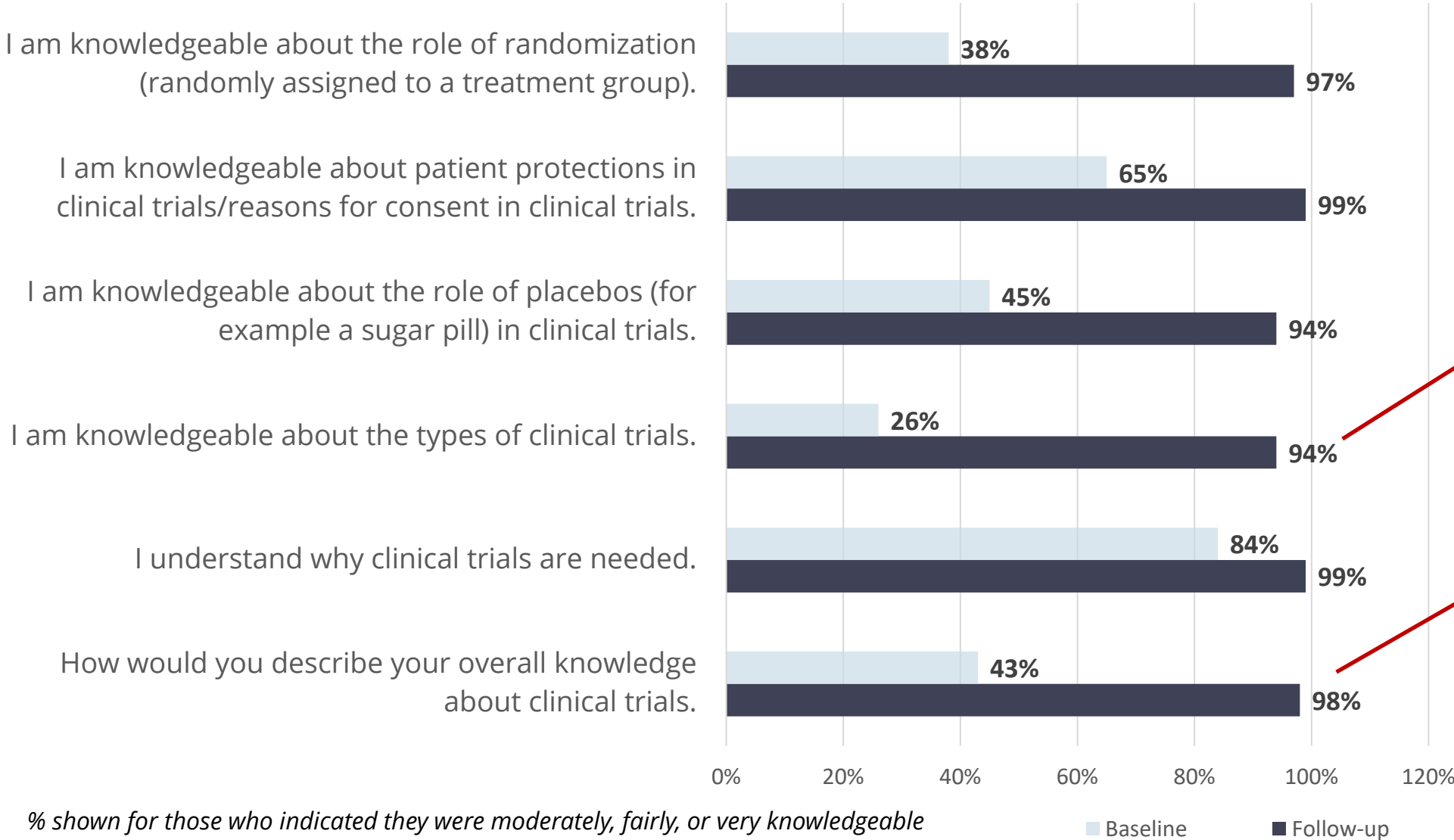
After the program, most people indicated they were **somewhat likely (31%)** or **extremely likely (54%)** to participate in a clinical trial.

Change in perceptions between baseline and follow-up

	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)

Program Metrics: Improved Knowledge



Key Learnings:

After completing the peer-mentor program, participants reported a **significant 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

*Mean differences significant ($p < .001$) for paired samples t-test (N=89)

Program Metrics: Increased Communication

Key Learning: After completing the peer-mentor program, participants reported **more communication** about clinical trials.

At follow-up, 65% 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 ($p < .001$).

39%

Of those who spoke with someone about participating in clinical trials by follow-up ($n=58$), they most commonly spoke with oncologists (62%), physicians (19%), or nurses (7%).



Inclusive Advocacy



**Get to know the
community**



Listen!



**(Truly) Meet
people where
they are**



**Be open and
authentic**



**Practice with
cultural humility**



**Seek
understanding
without
judgment or
labeling**



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Your Involvement

**“The time is always right
to do what is right.”**

Dr. Martin Luther King Jr.



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**thank
you!**

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