

# Perceptions of Cancer Clinical Trials Among Racial and Ethnic Minority Cancer Survivors

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## Background

- There are significant challenges with recruiting racial/ethnic minority patients, who are often underrepresented in this research, into cancer clinical trials (CCTs).

## Aims

- The objective of this study was to compare perceptions about CCTs among the largest racial and ethnic groups in a US-based cancer registry sample.

## Methods

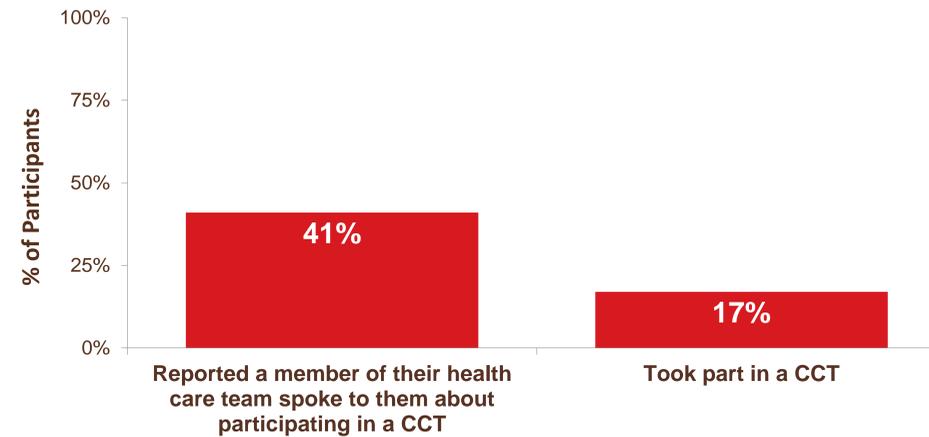
- 3,167 individuals diagnosed with cancer, enrolled in the Cancer Support Community's Cancer Experience Registry, answered questions about their experiences with and views on CCTs. Participants provide sociodemographic information and rated their level of agreement (0 = *strongly disagree* to 4 = *strongly agree*) with eight statements related to CCTs.
- Individuals that endorsed Hispanic or Latino ethnicity were coded as such regardless of race. Black or African American, Asian, and White racial groups consist of non-Hispanic or Latino individuals only.
- Bivariate associations between sociodemographics and CCT item ratings were examined. MANCOVA was used to determine associations between race and ethnicity and beliefs about CCTs after controlling for significant covariates, as well as age and gender. Statistical significance was adjusted for multiple comparisons with Bonferroni corrections.

## Participants

|                                  | <i>N</i> = 3167 | Mean/ <i>n</i> | SD / % |
|----------------------------------|-----------------|----------------|--------|
| Age (years)                      |                 | 57             | 11     |
|                                  |                 | Range: 20 – 91 |        |
| Female                           |                 | 2379           | 79%    |
| College degree or higher         |                 | 2048           | 68%    |
| Non-Hispanic or Latino Ethnicity |                 | 3073           | 97%    |
| White                            |                 | 2766           | 87%    |
| Black or African American        |                 | 108            | 3%     |
| Asian                            |                 | 44             | 1%     |
| Multiple races                   |                 | 32             | 1%     |
| Hispanic or Latino Ethnicity     |                 | 94             | 3%     |
| White                            |                 | 52             | 2%     |
| Black                            |                 | 3              | <1%    |
| Asian                            |                 | 1              | <1%    |
| American Indian or Alaska Native |                 | 7              | <1%    |
| Other                            |                 | 20             | <1%    |
| Multiple races                   |                 | 8              | <1%    |
| Time since diagnosis (years)     |                 | 5              | 7      |
| Ever experienced recurrence      |                 | 692            | 22%    |
| History of metastatic disease    |                 | 445            | 14%    |
| Treatment history                |                 |                |        |
| Surgery                          |                 | 1943           | 61%    |
| Chemotherapy (past)              |                 | 1858           | 59%    |
| Chemotherapy (current)           |                 | 265            | 8%     |
| Radiation therapy (past)         |                 | 1369           | 43%    |
| Radiation therapy (current)      |                 | 65             | 2%     |

## Results

### Cancer Clinical Trials Participation and Communication



- Fewer than half (41%) of registrants reported that a member of their health care team spoke to them about participating in CCTs
- 17% reported that they took part in a CCT
- The proportion of registrants that reported a member of their health care team spoke to them about participating in CCTs did not differ by race or ethnicity ( $ps > .05$ )

### Beliefs and Perceptions about Cancer Clinical Trials

| Belief  | Number of Participants (n) | Percent of Participants |
|---|----------------------------|-------------------------|
| Feeling uncomfortable with being randomly assigned to a treatment ( $n = 3033$ )                          | 1846                       | 61%                     |
| Fearing receiving a placebo ( $n = 3020$ )  | 1714                       | 57%                     |
| Fearing side effects that may come with treatment ( $n = 3002$ )  | 1516                       | 51%                     |
| Believing that health insurance would not cover a cancer clinical trial ( $n = 2917$ )                    | 695                        | 24%                     |
| Believing that there are not any clinical trials available in the community ( $n = 2958$ )                | 578                        | 20%                     |
| Fearing being used as a “guinea pig” and mistrusting the medical establishment ( $n = 3024$ )             | 521                        | 17%                     |
| Believing there are logistical barriers making it impossible to fulfill trial requirements ( $n = 3009$ ) | 539                        | 18%                     |
| Not understanding what clinical trials are ( $n = 3010$ )   | 285                        | 10%                     |

Note: % indicating Agree or Strongly Agree

- More than half (61%) of registrants reported feeling uncomfortable with being randomly assigned to a treatment in a cancer clinical trial
- Many registrants expressed strong fear about the chance they would receive a potentially ineffective placebo (57%) and about side effects (50%)
- Almost a quarter of registrants (24%) believed that their insurance would not cover a trial, despite rules requiring many insurance providers to consider a trial as they would any other form of treatment

### Associations between Race and Ethnicity and Beliefs about Clinical Trials

| Factor             | Wilks' Lambda | F(18,6693) | p     |
|--------------------|---------------|------------|-------|
| Race and Ethnicity | .970          | 4.026      | <.001 |

- The effects of race and ethnicity on the beliefs and perceptions of CCTs are significant, even after controlling for the effects of age, gender, education, and income.

| Predictor (compared to White participants) | Unstandardized beta | p | Part eta <sup>2</sup> |
|--|---------------------|---|-----------------------|
|--|---------------------|---|-----------------------|

**Not understanding what clinical trials are**  
( $F(3,2371) = 18.07, \eta^2 = .071, p < .01$ )

|                           |      |       |      |
|---------------------------|------|-------|------|
| Black or African American | .433 | <.001 | .005 |
| Asian                     | .760 | <.001 | .007 |
| Latino or Hispanic        | .450 | .001  | .005 |

**Fearing being used as a “guinea pig” and mistrusting the medical establishment**  
( $F(3,2371) = 10.29, \eta^2 = .042, p < .01$ )

|                           |      |       |      |
|---------------------------|------|-------|------|
| Black or African American | .313 | .019  | .002 |
| Asian                     | .570 | .006  | .003 |
| Latino or Hispanic        | .645 | <.001 | .008 |

**Believing that health insurance would not cover the cost of a CCT**  
( $F(3,2371) = 4.52, \eta^2 = .019, p < .01$ )

|                           |       |      |      |
|---------------------------|-------|------|------|
| Black or African American | -.299 | .029 | .002 |
|---------------------------|-------|------|------|

\*Controlled for age, gender, education, and income  
\*\*Significant associations only are displayed

- Mistrust of the medical establishment and fear of being used as a “guinea pig” was a stronger belief among Black, Latino, and Asian participants
- All racial and ethnic minority participants more strongly endorsed lack of understanding of clinical trials compared to White participants ( $\beta = 0.44, 0.43, 0.67$  for Black, Latino and Asian, respectively;  $ps < .01$ )
- Lower income and lower level of education remained associated with negative beliefs and misconceptions about CCTs

## Implications and Conclusions

- While the proportion of cancer survivors reporting that their health care team discussed CCTs did not differ by race, there is elevated mistrust among ethnic and racial minorities about the medical establishment and fear of being used as a “guinea pig” in CCTs, as well as perceived poorer understanding of CCTs. Fear of receiving a placebo was consistently high across racial and ethnic groups.
- Race and ethnicity play a small yet statistically significant role in beliefs and perceptions about CCTs; future research needs to explore other factors contributing to differences in CCT perceptions.
- These findings highlight important outreach and educational opportunities for healthcare providers and patient advocacy organizations, including comprehensive treatment decision counseling that is sensitive to survivors' diverse needs and concerns.

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- The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org)