

Improving Lung Cancer Clinical Trial Enrollment



Guidance for Developing Health Promotion Materials

Contents

<i>Executive Summary</i>	3
<i>Background</i>	5
<i>Research Methods</i>	6
<i>Final Assets</i>	26
<i>Campaign Feedback Survey</i>	27
<i>Conclusion</i>	32
<i>Acknowledgements</i>	32
<i>Appendix</i>	33

Executive Summary

Much progress has been made in the early detection and treatment of lung cancer. Advancements in cancer care cannot be made without robust clinical research studies, or clinical trials. Clinical trials are a vital part of the lung cancer treatment armamentarium and may be the most appropriate treatment option for someone facing lung cancer. However, there are inequities in the distribution of patients who participate in cancer clinical trials, with communities of color, including Black Americans, being underrepresented. There are many factors which impact this disparity, such as the long-standing history of [racial bias in healthcare](#) which impacts access to care and trust in providers and lack of awareness of clinical trials.

In early 2021, the American Lung Association embarked on a health education program aimed at improving **awareness** and **trust** of lung cancer clinical trials among Black Americans and encouraging Black Americans to **act** by talking with their doctor about clinical trials. *Awareness Trust and Action* began with a research phase consisting of a literature review, landscape survey, key stakeholder interviews and focus groups. The research phase confirmed that many Black Americans are concerned about the safety of a clinical trial and being treated as a “guinea pig.” The data show the notion of participating in a clinical trial elicits an emotional response among Black Americans with the primary emotion being fear. There is also a lack of awareness and understanding about clinical trials, how they work and their benefit. Black Americans may also face logistical barriers to participation like transportation, time off work and family responsibilities.

The data show Black Americans may be fearful of clinical trial participation because of past abuse of Blacks in healthcare like the ethically unjust USPHS Syphilis Study at Tuskegee or the many injustices Henrietta Lacks and her family endured. However, many Black Americans face present day racism in healthcare, and do not need to call on the memory of events that occurred several decades ago to conjure feelings of mistrust towards the U.S. medical system.

In addition to understanding the barriers to participation, the research phase of the project also gathered information about the most appropriate messages to improve trust and awareness and encourage Black Americans to take action by speaking to their doctor about clinical trials. The data show messages must come from trustworthy sources and spokespeople should look like the target audience, listing the three most trusted messengers as a physician, a faith leader and a lung cancer patient who participated in a clinical trial.

The findings also show that the most effective way to address fear is through straightforward, educational messaging. Communications build trust when they inform rather than persuade. It is important to avoid emotionally charged language or images, as the message may appear coercive instead of informative.

In early 2022, building on findings from the preliminary research phase, the American Lung Association released several public service announcement style videos as well as an informative campaign landing page available at [Lung.org/trials-and-you](https://www.lung.org/trials-and-you). A campaign feedback survey among the target audience revealed the campaign assets improved attitudes toward clinical trials and encouraged many survey participants to act. Survey participants found the messages educational, straightforward, honest, and delivered by trustworthy messengers. Participants suggested featuring more stories from patients focusing on the research, trial outcomes and long-term progress.

Many stakeholders play a role in improving diversity in lung cancer clinical trials. Research shows that Black Americans, who make up roughly 14% of the U.S. population, account for only 3.1% of participants in clinical trials for cancer drugs.¹ For lung cancer clinical trials specifically, there was even a decline in the percentage of Black participants between 2011 and 2015², a trend we hope to see reversing since many stakeholders have a renewed commitment to addressing this disparity.

Patient advocacy and public health organizations should use their trusted voice to share clear and direct educational messages about lung cancer clinical trials and harness the storytelling power of their advocates to share personal lung cancer clinical trial stories. There is also a role for these organizations to bridge the gap between the research bench and the patient by sharing how a drug is developed and the role of clinical trials in that process.

Grassroots organizations and patient navigators are vital in helping advocate for patients and reduce barriers to care. Additionally, healthcare professionals need to recognize the role institutional racism plays in impeding health equity and how their own biases may influence clinical trial enrollment.

Lastly, those involved in running a clinical trial should take steps to remove barriers like allowing care at satellite locations, alleviating financial burdens of participation, and ensuring clinical trial enrollment materials are easy to understand so potential participants can make an informed decision.

1. Loree JM, Anand S, Dasari A, et al. Disparity of Race Reporting and Representation in Clinical Trials Leading to Cancer Drug Approvals From 2008 to 2018. [published online August 15, 2019]. *JAMA Oncology*. doi: 10.1001/jamaoncol.2019.1870.

2. Duma, N., Aguilera, J. V., Paludo, J., Haddox, C. L., Velez, M. G., Wang, Y., Leventakos, K., Hubbard, J. M., Mansfield, A. S., Go, R. S., & Adjei, A. A. (2018). Representation of minorities and women in oncology clinical trials: Review of the past 14 years. *Journal of Oncology Practice*, 14(1), e1-e10. <https://ascopubs.org/doi/abs/10.1200/JOP.2017.025288>.

Black patients deserve to benefit from the cutting-edge therapies lung cancer clinical trials may offer. Furthermore, when more Black people are represented in a study, researchers can learn about the best treatments for Black people. And then, Black patients are more likely to receive lung cancer treatment that may save or extend their lives. To communicate this vital information and make system changes, the lung cancer and clinical trial community should recognize historical and present-day influences on decision making and address concerns by mobilizing trusted community voices to share personal stories and clear education about clinical trials.

Background

The American Lung Association recently launched its campaign, *Awareness Trust and Action (ATA)*. The goals of this campaign are to raise awareness among Black lung cancer patients/caregivers, as well as the larger Black community, about the availability and importance of clinical trials as a treatment option for lung cancer, address misconceptions and mistrust around clinical trials and convey their value as a potential treatment option and empower Black Americans to talk with their doctor about lung cancer clinical trials.

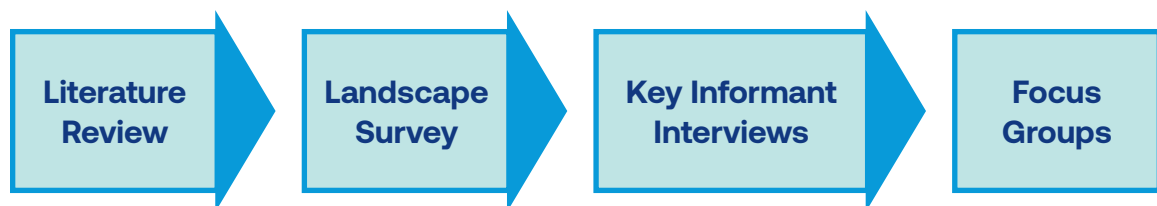
[Lung cancer](#) is the number one cancer killer of both men and women in the United States. Black Americans in particular with lung cancer are less likely to be diagnosed at an [early stage](#), less likely to receive [surgical treatment](#), and less likely to receive any treatment at all compared to white Americans.³ This leads to poorer outcomes from lung cancer for Black Americans.

But there is hope. Lung cancer research is moving at a rapid pace. We are learning more about how lung cancer develops, and researchers are working hard to find treatments to help save and extend the lives of lung cancer patients. Sometimes the most appropriate [treatment option](#) for a lung cancer patient is a clinical trial, however, Black Americans are underrepresented in clinical trials. This disparity leads to major public health issues. First, a clinical trial might offer access to novel treatments that may save or extend the lives of the patient. Reduced access to treatment leads to poorer lung cancer outcomes. Second, it is important for researchers to learn how different types of people react to new treatments or interventions being studied to have a more accurate perception of how the drug or intervention will impact a larger population. Low lung cancer clinical trial enrollment among Black Americans is a complex topic which will take a multi-pronged approach to address. One of the largest barriers to participation is low awareness of lung cancer clinical trials and misconceptions about participating in a trial.

3. <https://www.lung.org/research/state-of-lung-cancer/racial-and-ethnic-disparities>

To address knowledge barriers, the American Lung Association released several educational assets, including three PSA-style videos, two longer videos and an informative webpage through its *ATA* campaign. The assets were promoted nationwide, with a focus on Black Americans and their families/caregivers living in the Chicago, IL, Philadelphia, PA and Houston, TX metro areas. The priority population represents a community with a high lung cancer mortality rate among the Black population that is also within proximity to a research institution—which helps ensure the key messages are received by a population who have a greater likelihood of being able to access a clinical trial. Prior to asset development, the Lung Association and its partners conducted a robust research phase to ensure the key messages were salient, culturally competent and informed by the target audience.

The research phase followed the following pathway with the findings from each activity informing the next.



Following the release of the assets, the program was evaluated using a **Campaign Feedback Survey**.

Black patients deserve to benefit from the cutting-edge therapies clinical trials may offer. Through the American Lung Association’s *ATA*, we strive to empower patients to speak with their healthcare providers about treatment options and make an educated decision about participating in a clinical trial. The findings from this campaign aim to inform future communications about clinical trials and health inequities in lung cancer among Black communities as well as in other disease states.

Research Methods

Literature Review

Prepared for the American Lung Association by the Research & Evaluation Group at Public Health Management Corporation (PHMC)

PHMC researched peer-reviewed journal articles related to clinical trial participation from the past five years, including a search focused on Black Americans and lung cancer trial participation.

Summary of Findings:

Black patients were consistently underrepresented in oncology clinical trials, with little to no increase in enrollment rates over the last decade. For lung cancer clinical trials specifically, there was a decline in the percentage of Black participants between 2011 and 2015. Barriers to participation were collected through focus groups, surveys, and document reviews. Feelings of distrust and exploitation from research institutions among Black Americans were common themes found in the reviewed literature that limited clinical trial participation of this group. Black Americans were also fearful of unequal treatment from doctors and unknown side-effects or outcomes from potential trials. There was a reported lack of awareness of clinical trials and disinterest due to overwhelming health concerns, family and/or other socioeconomic conditions. Black patients preferred hearing information about clinical trials from their doctors or community organizations like their church. They appreciated clear and transparent information on clinical trials, through discussions with other trial participants, testimonials, illustrations, and images, to aid with their understanding of and decision-making around clinical trials. Addressing medical and research mistrust can help improve lung cancer clinical trial enrollment. Patient navigators or research liaisons may help overcome barriers to cancer clinical trial participation for this group by assisting with financial, transportation, and familial concerns, as well as other social determinants of health.

A full list of the literature reviewed and findings specific to each study can be found in the *Appendix*.

Landscape Survey

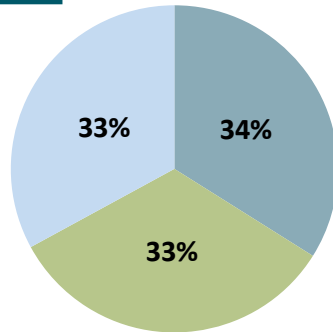
Prepared for the American Lung Association by the Research & Evaluation Group at Public Health Management Corporation (PHMC)

PHMC worked with the American Lung Association to create an online landscape survey to gather information about lung cancer clinical trials among Black individuals in the Chicago, Houston, and Philadelphia metro areas. The online landscape survey was distributed by Alchemer to paid panel respondents. The landscape survey was comprised of closed and open-ended questions and lasted approximately 7–10 minutes. It gathered demographic information and current awareness, attitudes, and behaviors related to clinical trial participation. The survey garnered 551 complete responses, with 504 respondents from the targeted metro areas. A summary of the survey results is below:

Clinical Trials Landscape Survey

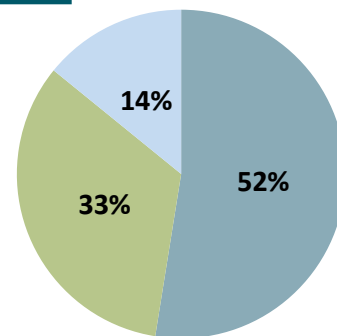
Summary Report: Findings from 504 respondents

Location



- Chicago, IL
- Philadelphia, PA
- Houston, TX

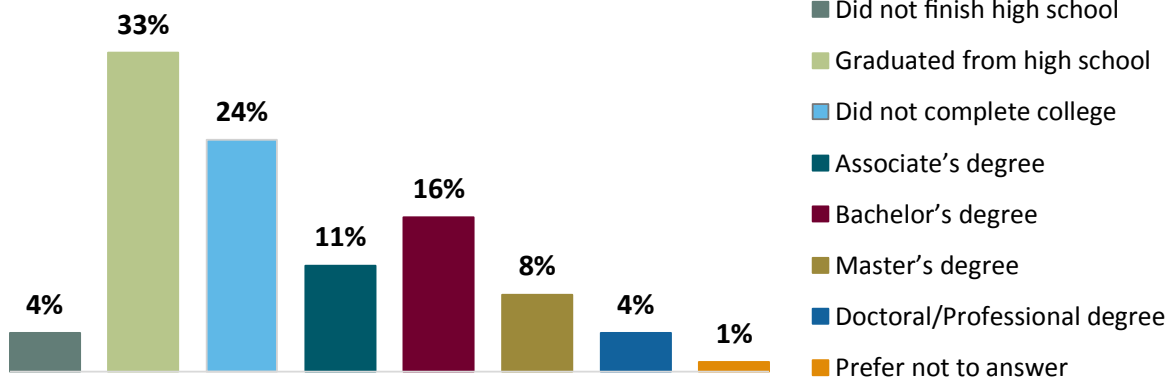
Age



- 18-35 years old
- 36-55 years old
- 56+ years old

Socioeconomic Status	%	Political Views	%
Low income	22%	Very liberal	18%
Lower-middle income	22%	Slightly liberal	17%
Middle income	34%	Moderate	39%
Upper-middle income	10%	Slightly conservative	10%
High income	8%	Very conservative	6%
Prefer not to answer	4%	Prefer not to answer	10%

Education Status



Chicago, IL



- Most likely to believe that taking part in a clinical trial will make them sicker
- Agrees most that their medical care will not be as good if they are in a clinical trial
- Most uncomfortable with random assignment to treatment
- Agrees most that Black patients are discriminated against in medical treatments and research studies

Philadelphia, PA



- Understands clinical trials the least
- Least willing to take part in a clinical trial
- Disagrees most that the benefits of a clinical trial outweigh the risks
- Disagrees most that clinical trials follow strict rules to protect patient safety
- Agrees least that their doctor would suggest they enroll in a clinical trial if it was the best option for them at the time

Houston, TX



- Agrees most that being part of a clinical trial could help other people of color
- Least afraid of getting a placebo instead of real medicine in a clinical trial
- Agrees most that all people who enroll in clinical trials are treated the same, regardless of race and ethnicity

Top 5 reasons for participating:

- 40%** Great relationship with doctor
- 38%** Discussions with prior participants
- 32%** Reliable technology
- 29%** More time to decide
- 27%** Ease of getting to appointments

Top 5 reasons for not participating:

- 45%** Fear of negative side effects
- 36%** Fear of the unknown
- 33%** Fear of mistreatment
- 25%** Lack of time for appointments
- 24%** Bad relationship with doctor

Top 3 information for decision-making:

- 46%**
Payment
- 34%**
Benefits
- 33%**
Time commitment

Top 3 ways to learn about clinical trials:

- 57%**
Doctor
- 31%**
Hospital waiting rooms
- 29%**
Online ads

Highlights and suggestions from the key informant interviews

"...patient-doctor relationship and trust is paramount in recruiting patients for clinical trials in this area, among this patient population."

"I think that most of the doctors the patients are going to encounter are not always going to be of the same race. So, the PSA has to include doctors of different race or ethnic background."

"But they do want some sort of openness about, 'Okay, we don't have it right, we don't always... We haven't always gotten it right in the past, we may not be perfect now, but we are trying to move forward and we are trying to address some of these concerns and issues.' So I think maybe not skirting around the issue of the reason why most of them don't want to participate is because they don't feel safe in those environments."

"That's what I would put in the PSA, I would say, it's really about advocating for yourself because then you're doing the awareness piece, you're doing the trust piece, and you're giving them the tools to take action. You're saying, "Hey, other people are benefiting from this. African Americans need to benefit from this." And here's what you do. Here's what we need to be doing, asking these questions, making sure they're acknowledging pain and family history or whatever, and then ask them to be an option for clinical trials."

So, this is where the PSA can be very helpful, even includes generations of family members, okay... for example, here is the patient, here is the wife or the children, and here is the grandchildren or something like that. And they all can be seen in the context of making a decision regarding the treatment plan for this patient. It helps send the message that anyone in that family can play a role in convincing that individual to participate in the trial. You don't even have to say it, you just have to show it."

"So I go out to the churches and the senior centers in the Black community and tell my story. So they see the example, how it works. So you can't argue against something that works, and then it becomes more credible... it's just more people have to be made aware of it in a practical way that they can see that it does work."

Stakeholder Interviews

The Lung Association conducted interviews with ten stakeholders to identify common themes that can be addressed with messaging intended to decrease the barriers Black Americans face with respect to lung cancer clinical trial participation.

The following qualitative analysis of the interviews is adapted from a report prepared by Daniel J. Woytowich, DrPH Candidate, MPH, MS.

► Methods

Sample and Data Collection

This qualitative analysis summarizes results from eight separate open-ended interviews; each of which lasted approximately 45 minutes. The interviews were largely free-flowing discussions with key stakeholders on issues they thought would be important to consider when trying to reach Black lung cancer patients who could benefit from clinical trial participation. Since there were two participants in two of the interviews, there was a total of 10 interviewees. Eight of the ten respondents identified as Black. Interviewees had a variety of backgrounds including previous patients and/or clinical trial participants, public relations personnel, patient advocates, oncologists, a thoracic surgeon, and a clinical trial coordinator. Some participants could be classified into more than one of the categories.

Interviews were conducted by two Lung Association employees and began by introducing the overall concept of the *Awareness Trust and Action* project and asking the participant to describe their background and its relation to lung cancer and clinical trial participation. Interviews mostly took shape organically, but some pointed questions reoccurred, such as:

“When considering the public service announcement (PSA), are there any messages you think would be particularly important in reaching the Black community with respect to lung cancer clinical trials?”

“Do you think the message should differ for older versus younger audiences?”

“Do you think the message should differ for men versus women?”

“Do you think posing the issue as one of social justice would be beneficial?”

Interviews were conducted remotely and transcribed during April and May 2021.

Data Management and Analysis

To ensure quality, every interview was watched in totality for the sole purpose of checking the accuracy of the transcriptions and making any necessary corrections. The interview videos were watched again to holistically assess them in their original context. Next, the transcriptions were analyzed using inductive content analysis, which is to say that themes were not decided or theorized upon before analysis. While going through the transcripts, important points and ideas were highlighted, and then categorized into emerging themes. All transcripts were reviewed one final time where all relevant nodes of information were checked for proper classification into the overarching themes.

▶ Results

The eight interviews yielded the five following themes:

- 1) Comprehensive education
- 2) Impact of family
- 3) Adult child caregivers
- 4) Influence on the broader Black community
- 5) The role of physicians.

Theme 1: Comprehensive education

The most common theme throughout all interviews was that there is a need for comprehensive patient education to assuage their hesitation and fears. The participants conveyed that there is still concern among the Black community about being used as a “guinea pig” or being “experimented” on. **All the interviewees expressed that comprehensive, blunt, and transparent information dissemination about what a clinical trial is in the present day would help dispel these negative outlooks.** One interviewee summed these sentiments up in one pertinent sentence:

You want to be sure that people understand what a clinical trial is and the distinction from just experimentation.

Some of the care providers interviewed said that a common concern of patients was the notion that clinical trials may be a “lesser” treatment alternative. These providers think it is important to convey to patients that just because a treatment is in the “trial” phase, it does not mean they are receiving sub-optimal care.

Some interviewees used the phrase “nothing to lose” when describing patients in advanced stages of their diseases with respect to their participation in a clinical trial. Informing patients about the cancer timeline and the decision-making process that goes into offering a patient a clinical trial may help dispel the myth that they are receiving a lesser treatment and more realistically orient their perception of the risk/reward ratio. Also, patients need to know that they can withdraw from the trial at any time with no repercussions. Another participant stated that they thought it would be important to tell patients that clinical trials, in addition to the extensive testing and oversight, have typically had input from communities, the government, physicians, and patient advocates before they are launched.

Communicating that people participating in clinical trials are monitored more closely than if they had not been on a trial could be important. Informing patients about results and data from the previous phases of the trial can be helpful, rather than being paternalistic and guarded with respect to the sharing of data. Providers and patients alike thought it important to explain the distinction between the different clinical trial phases. One participant noted that more time and energy should be spent on educating patients asked to participate in a Phase 1 clinical trial since there is less available background data.

One patient participant was blunt about the fact that they would have been more open and maybe even eager to enroll in a clinical trial if their doctor had explained to them the history of clinical trials, the potential benefits of them, the advancements made concerning ethics, the oversight protocols employed during the process of creating the medication, and specifically why the physician believes they would be a good candidate for that trial based on their clinical history. In the words of another participant:

It's very helpful to inform, rather than persuade.

There was sentiment that while past events that have contributed to the lack of trust the Black community currently has in the medical system (e.g., Tuskegee) should be acknowledged, it is more important to focus on these events with respect to how they have informed the safety and ethical standards we have in place today. It was suggested to give the patient information about the pharmaceutical company and funding so they can do the research they need to feel comfortable with the entities behind the trial. Another important topic that came up was the need to give patients information about how to navigate the clinical trial process. As one participant put it:

Give them the tools they need to take action.

Participants acknowledged that Black patients and other historically underrepresented patients are not asked to participate in clinical trials at the same rates as others. This may be due to doctors not asking them or because they frequent healthcare facilities

that do not have the requisite infrastructure to do clinical trials. In these cases, giving the patients information about how to seek clinical trials for themselves on the internet and find clinical trial navigators and/or patient advocates that can help them find a suitable clinical trial was suggested. Therefore, education can not only help ease fears and concerns but also give patients the tools they need to ask about clinical trials proactively or even find them on their own. Lastly, it was brought up that some patients may have concerns about if clinical trials will be covered by insurance, or if enrolling in a clinical trial will affect their current insurance premiums or deductibles. Patients need to be given information about any financial implications of enrollment.

Theme 2: Impact of family

It was discussed how some older patients, especially men, might not be particularly interested in clinical trials for their own sake, but may make the decision to enroll in a trial so they can continue to “be there” and “provide” for their family. One cancer survivor said this about their decision to enroll in a trial:

My daughter was five years old at the time. So that was one of the reasons why I was really motivated to keep trying ...

It was especially noted that older men sometimes “shut down” after learning of a cancer diagnosis, due to feeling like their ability to provide for their family, which they viewed as one of their duties, was taken away. Several participants noted that framing the clinical trial as a tool a patient could employ to autonomously continue providing for their family may be helpful. In a sense, men will be fulfilling their familial duties by exhausting all treatment possibilities to survive and continue to provide. Women were also noted as being highly motivated by family (i.e., still being there to provide for, mentor and help raise their children and/or grandchildren). Several participants thought encouraging women to participate in clinical trials would require less effort than the men.

Theme 3: Adult child caregivers

This theme is intertwined with Theme 2, but in a way is the opposite side of the coin. Some participants noted the potential benefit to specifically targeting the adult child caregivers of older adult lung cancer patients. It was thought that adult child caregivers could help their parents understand the science, reasoning, potential benefits and health system navigation required for them to feel comfortable enrolling in a trial. This could be especially helpful with elderly patients that may not have a high degree of health literacy. Having a child that can act as an advocate is also important for helping make important decisions during a time when the patient may be shocked by their diagnosis and not thinking clearly. Adult child caregivers may also be able to give insight to physicians concerning how symptoms and side effects are manifesting at home, which can give the physician more clarity about how to treat the patient. Caregivers can better help

their parents understand the familial consequences of their decision to enroll, or not enroll, in a clinical trial.

Theme 4: Influence on the broader Black community

Several interviewees thought that framing participation in a clinical trial as an endeavor that could benefit the broader Black community might be prudent. This theme buttresses with Theme 1 in that it would involve educating patients on how clinical trials need data input from Black Americans to create a research base concerning how the treatment works in the Black community. Education on this issue can also help alleviate skepticism the patient may feel about being “targeted” for a clinical trial. **Rather than feeling like they are being asked to participate because they are being taken advantage of and experimented on, they can more easily understand that it is important to have Black Americans and other historically underrepresented populations participate in clinical trials for the sake of equity in data production and equity of opportunity for cutting-edge treatments.**

There were some contrasts concerning how respondents felt about generational effects of the perception of clinical trials as a social justice issue. Some felt that framing participation in clinical trials as a social justice issue would work better with younger lung cancer patients due to the current climate’s renewed focus on social justice, whereas older cancer patients might feel like they have already fought that fight and are now more so focused on family issues rather than societal injustices. However, other interviewees felt the opposite, and thought the older generation of Black Americans that lived through the civil rights era would indeed be motivated to participate if they felt that clinical trials could benefit the Black community.

A suggestion was made that if social justice were a topic addressed, it would be important to:

... not come on too strong.

This respondent explained that it may be counterproductive to frame the issue too heavily as one that could benefit the Black community for fear that it could be construed as manipulative or pandering. **The interviewee thought that being overbearing with this messaging might make Black Americans more skeptical and suspicious of a nefarious reason behind them now being catered to so heavily, when in the past they were traditionally ignored by the medical establishment.**

Several participants also pointed out that it would help if they were presented information by Black cancer survivors or made part of a support group comprised of other Black cancer survivors that have been in clinical trials. **This would enable them to hear the unfiltered truth about how the survivors, as members of the Black community, were treated as part of the clinical trial.**

Theme 5: The role of physicians

Another recurring theme was that patients' long-time physicians must do a better job of educating their patients about potential opportunities like clinical trials. One former patient specifically stated that if they had been introduced to the idea of a clinical trial at any point in their ongoing care with their regular physician that they would have been more open to and accepting of the idea of participating when this topic surfaced after their diagnosis. After diagnosis, new information and new options come too quickly during what is an incredibly stressful and traumatic time. As one oncologist stated:

We know one problem is that some physicians are just not having these conversations with patients.

Several respondents said that hearing this information from long-time primary care physicians could play a powerful role due to the rapport they already have with the patient. This was especially noted to be important with respect to Black patients, who traditionally have distrust in the health system. One physician stated:

Although some patients don't fully trust the medical establishment, or even the system, the healthcare system, they do put a lot of trust in you as their provider.

Physicians must be better educated about the history Black Americans have experienced in the American health system which would help them be more understanding of the reticence Black Americans might display with respect to novel treatments. Understanding this history can help primary care physicians, who in a way are the gatekeepers of the health system, appreciate the importance of engaging in the clinical trial recruitment and navigation process. Physicians and oncologists should work in concert to get Black patients access to trials if they are part of health systems where patients are not typically availed of that opportunity. Most interviewees thought it could be prudent to have some messaging targeted at physicians included in the PSA as well.

► Recommendations for PSA

Due to the variety of people involved in the clinical trial process in addition to the patient (e.g., their family, primary care physician, and oncologist) that were deemed important during the interviews, it was suggested by some respondents to create a PSA involving a group of these people discussing a clinical trial with a patient. In this manner, patients, familial caregivers, and primary physicians could all be educated by observing a conversation in a real-life context. One interviewee also suggested that representing different generations of family members in the PSA could be beneficial. Highlighting grandchildren for instance might be helpful for reaching patients that for whatever reason may be more motivated by them as opposed to adult children. For example,

the desire to see their grandchild's first day of school, first communion, etc. could be leveraged. This messaging could take place in the context of a hospital room where the primary care physician and/or oncologist are working in concert and educating the patient and their family on issues deemed important in the thematic analysis, such as background information on clinical trials, the differences between clinical trial phases, the testing protocols that are gone through prior to the start of a trial, the fact that clinical trials are not a lesser form of treatment, and their potential benefit to the patient, their family, and the Black community. It was important to most interviewees to have the messaging come from a member of the Black community, and if possible, a member of the Black community that has been through the clinical trial process. Having the PSA involve a whole group of people exchanging information, some of which is regarding social justice, would also reinforce the concept of how clinical trials can benefit the broader Black community.

Having a Black physician disseminating information to a cancer patient and their family about the possibility of a clinical trial would not only be a mode of delivering the PSA's information, but it would also provide an example to primary care physicians about how they too can go about having a similar conversation in their own practices. It would provide a positive example of what patients, families, and physicians should be looking for in their physician/patient relationships during the clinical trial recruitment process. The patient and patient's family can engage in question/answer exchanges with the physician in the PSA, which will serve as real-time examples of questions the audience can ask to better navigate their personal clinical trial process.

Throughout the interviews there were mixed feelings about the proper placement of financial incentives in the recruitment process. There did seem to be consensus, however, that trust with the physician and trust with the system must be bolstered before offering any financial incentives; otherwise there exists the risk of making the patient feel as though they are being manipulated. When delivering the information during the PSA, it was also recommended that the person giving the information not use phrases like "if I were in your shoes" unless they were a Black patient that had experienced lung cancer. However, there were slightly differing opinions on this as well. One interviewee thought it could be helpful to have a physician say something to the effect of "if a member of my family was in your situation, this is what I would want them to do". Very specific and sensitive wording seemed to be the key if this type of messaging was to be employed.

In conclusion, the most salient messaging guidance emerging from the interviews was:

- Provide comprehensive and matter-of-fact information on the clinical trial process, the safety measures and regulations in place, how clinical trials in their current form can help close disparities in the health system, details about the different phases of trials, and the idea that clinical trials are opportunities to advance and improve patient care, etc.

- Have the primary message come from a Black physician, or Black survivor of cancer who has participated in a clinical trial.
- Focus on the importance of family, both with respect to the family helping the patient through the process and the patient reciprocally being there for the family.
- Empower patients and their families to navigate the health system to seek out their own trials if they are not being availed of this opportunity either by their physician or health system.

Focus Groups

The Lung Association used the findings from the Literature Review, Landscape Survey and Key Informant Interviews to draft fourteen Key Messages. The Lung Association led three cohorts of focus groups in a discussion of the messages and a summary of the reactions to the messages are presented below.

MESSAGE 1: Right now, Black Americans are woefully underrepresented in clinical trials.

Cohort A: Acknowledge it is a true statement; “woefully” is not easy to process and not used in everyday language

Cohort B: This message needs explanation. Why are they woefully underrepresented? It should be paired with something explanatory; “Woefully” kicks you in your chest and makes you concerned

Cohort C: “Woefully” sticks out in a negative sense.; “Right now” makes it seem like it hasn’t been going on for a while and won’t be going on in the future

Key Takeaways: Avoid time stamps, avoid adverbs, present the problem with some background or history

MESSAGE 2: It is time to dispel the myth that people who participate in clinical trials are guinea pigs. This fear has kept many Black Americans from participating in clinical trials and gaining access to potentially life-saving treatment.

Cohort A: Mentioning guinea pigs reinforces the idea; guinea pigs is startling; The way the message is framed makes it seem like it is blaming Black Americans for the way they think; Wording should validate the concern they are being experimented on; The word “many” doesn’t acknowledge that there are different reasons why people participate

Cohort B: People who want their life saved won't have much of a problem with what happened in the past; Cancer treatment seems different than a vaccine trial; People 65 and older will have a different view of clinical trials than someone younger, younger people will be more eager to enroll, "is this something that is going to help me?"; Someone has had to go through a clinical trial to get me my chemo, education helps dispel fear, you are part of the process to continue the development of treatment that may save your life

Cohort C: Guinea pigs stands out in a negative way; Physician says that it is something people identify with strongly even if it is not "palatable"

Key Takeaways: Mentioning "guinea pig" produced negative emotions for many people, perhaps because being treated like a "guinea pig" is a large fear. The target audience should not be made to feel responsible for this fear. In general, this is a negative message that is not as palatable as others.

MESSAGE 3: Black Americans should have better access to cutting-edge cancer treatments and awareness of clinical trials is the first step.

Cohort A: Positive response to this message because it focuses on the benefit; Cutting-edge resonates with people

Cohort B: Awareness and education are the first steps, not just awareness

Cohort C: Like the positivity of this message and the clarity, starting off in a positive way and getting to the point is helpful; Previous messages were a bit condescending whereas this one is positive and to the point; recommending replacing "is the first step" with "is important"

Key Takeaways: Cutting-edge treatments is a phrase that is well received. The clarity and positivity of this statement resonated well with participants. Consider rephrasing to say: Black Americans should have better access to cutting-edge cancer treatments and awareness and education are important first steps.

MESSAGE 4: Black Americans deserve access to accurate information about clinical trials so we are empowered to make healthcare decisions.

Cohort A: "Accurate information is vital" reads better than "deserves;" This statement needs history to explain why Black Americans haven't had access

Cohort B: Messages should be very clear so the person knows exactly what they are getting into and they aren't surprised; Person should be able to picture in their mind what the possibilities are, this builds trust

Cohort C: Statement is honest, recommending adding “clear and accurate;” Suggests saying “make the best healthcare decisions for you”

Key Takeaways: Statements that infer Black Americans have received inferior care compared to their white counterparts need to be carefully coupled with information about why this is the case and what is different. Consider removing emotional words like “deserve” and stating clearly that the purpose of the PSA is to provide accurate and clear information so Black Americans feel empowered to make the best healthcare decisions for themselves.

MESSAGE 5: Clinical trials give patients a novel opportunity for cutting-edge cancer treatments, rather than continuing a treatment that isn’t working or starting a treatment that isn’t likely to work.

Cohort A: Why would someone continue a treatment that isn’t working?; Distracting to think of people who might be using a treatment that isn’t going to work; Perhaps share novel and new, easier to understand

Cohort B: Drive home the point that clinical trials aren’t the last house in the street, they can be an integral part of treatment, you can benefit at any stage

Cohort C: The word novel might be problematic for health literacy; replace with “new;” Felt this was a strong message

Key Takeaways: Bringing in the idea that treatment isn’t working or won’t work can be distracting, confusing and inaccurate. It might be emotionally compelling, but it might be better to stick with the first part of the sentence.

MESSAGE 6: Each participant in a clinical trial is treated with the highest level of care.

Cohort A: Helps reinforce clinical trials are associated with care

Cohort B: Excellent!

Cohort C: Clear and to the point

Key Takeaways: This is an important point that should be made somewhere in the PSA.

MESSAGE 7: Each participant in a clinical trial is treated with the highest level of care. It is important to recognize the clinical trials in today's world are committed to keeping ALL patients safe.

Cohort A: "Today's world" acknowledges the past and that is important

Cohort B: The "all" is off-putting, a reminder of the inequities, keep patients safe or keep every patient safe does need to be emphasized and is better than emphasizing "all"; Must gauge the level of knowledge and awareness about past atrocities before leading with a message that acknowledges the past

Cohort C: Like the use of the word "safe;" Confusion about whether safe means the enrollee would have adverse effects or not, people might assume "safe" means you leave how you came in which might not be true; Clinical trials today is better than "in today's world" which can feel negative; It is important to acknowledge the past but saying "today's world" is not enough acknowledgement

Key Takeaways: Avoid timestamp, the sentiment is important but the word "safe" is vague and could be misleading and the emphasis on "all" can be triggering.

MESSAGE 8: The clinical trials you think of from the past are not what clinical trials are today. They are highly monitored for safety. Clinical trials are not alternative treatments but can provide access to potentially lifesaving treatment. Don't discount a clinical trial without getting the facts.

Cohort A: It is a clear and important message; too long for written; "Don't discount" is very straightforward and culturally appropriate; Be careful not to accuse people of thinking a certain way ... i.e.: "...you think of...;" Maybe replace "trials" with "studies;" "Studies" alludes to the past more

Cohort B: The first sentence assumes too much negativity, perhaps say "You MAY think of from the past;" Establishing it is not an alternative treatment is important, "Don't discount a clinical trial without getting the facts" is a compelling and important message

Cohort C: Didn't favor "don't discount a clinical trial;" Try and make the last sentence more positive like "Talk to _____ about a clinical trial;" Conflicting views on the importance of acknowledging the past. Some suggest just moving forward or allowing history to come up in conversation with the doctor

Key Takeaways: Avoid statements that assume, opt for inserting “may think of from the past;” Some participants really liked “Don’t discount a clinical trial without getting the facts” while others found it too negative and wanted something more action oriented. Consider using the word “studies” to replace trial.

MESSAGE 9: Participation = Representation. Clinical trials lead to new drug approvals, and it is important the experience of Black patients is considered before the drug is approved.

Cohort A: Representation resonates well within the Black community; It is a clear message

Cohort B: The word “experience” is vague, change experience to “input;” Use the word “inclusive” somewhere

Cohort C: This message was well received. Participation = Representation is a strong sentiment; The second sentence gives ownership and shows people they give something to contribute

Key Takeaways: Participation = Representation is a strong and catchy message; some participants found the word “experience” to be vague and opted for input.

MESSAGE 10: Participating in a clinical trial might give you access to cancer care that could save or extend your life. That means more precious time with your loved ones.

Cohort A: Offers a different perspective; No messages mention quality of life which is one benefit of clinical trials

Cohort B: Sounds like “do it or you are going to die;” Bring up quality of life as well; Too reminiscent of death; First sentence over promises and sound coercive

Cohort C: Could be overpromising; The fight for life doesn’t always translate to precious time; First sentence is good as is, second sentence seems like “bait”

Key Takeaways: This message evoked strong reactions because it reminded people of death and seemed coercive, it also might not be accurate; consider also mentioning quality of life.

MESSAGE 11: When you participate in a clinical trial, you are part of the greater good. You get access to high-quality cancer care while also paving the way for Black patients in the future.

Cohort A: This one has good intentions but isn't landing right; "Greater good" seems a little manipulative; Message would be better/clearer; Suggests "You are creating an opportunity for future black patients"

Cohort B: Remove part sentence with the greater good, perhaps switch sentences around: "You get this and, in the process, you give back;" You are supporting someone else in the future, you are providing information to help support someone else's treatment in the future

Cohort C: Liked this one because it was very positive; Found "greater good" very motivating

Key Takeaways: Some participants found "greater good" coercive but the sentiment important and motivating; Consider rephrasing to "You are creating an opportunity for future black patients."

MESSAGE 12: Why is it important for Black Americans to consider clinical trials?

- **Black patients deserve to benefit from the cutting-edge therapies clinical trials may offer.**
- **The Black patient experience matters in research. When more Black people are represented, researchers can learn more about the best drugs to treat Black patients.**

Cohort A: Clear, convincing message; Gets me to think about clinical trials; Cutting-edge is a strong adjective; Both reasons are compelling; Rephrase so "Black patients" isn't overused; "Deserve to benefit" is a strong message; "Black patient experience matters" is also a strong message; Not everyone views themselves as a patient so be more inclusive; "When WE are represented they can learn about messages to treat US" is better than labeling someone as a patient; Medications is better than drugs

Cohort B: Feels like this message separates Blacks from everyone else, is a reminder of the inequities; Black people are not the only ones underrepresented, everyone needs to participate. It has to be inclusive so we know it will be effective for everyone; Some cohort members were in favor of being clear there are differences for Blacks vs Whites and we need to meet people where they are; Very important not to be coercive/make promise; PSA messages should be factual like the experience of enrolling in a clinical trial; Cutting edge/emerging are good options, cutting/edge more powerful

Cohort C: Suggest using treatments instead of drugs, otherwise very clear; The Black patient experience is very compelling; Black patients “deserve” makes it seem like they aren’t getting cutting edge therapy; “When more Black people are represented, researchers can learn more about the best treatments to treat Black people and therefore Black patients will get better access to cutting-edge cancer therapies”

Key Takeaways: Using inclusive language like “we” and “us” is better than labeling someone a patient; medications/treatments is better than the word “drug”; words like “deserve” are emotional and can bring remind people of inequities.

MESSAGE 13: I want you to feel empowered to talk to a trusted doctor about treatment options and make an educated decision about participating in a clinical trial.

Cohort A: Don’t need to say “trusted doctor”, you wouldn’t go and talk to someone you wouldn’t trust, “When you talk to YOUR doctor, I want you to feel empowered and informed”; the way it is written assumes that because a patient is Black, they aren’t in the care of a doctor

Cohort B: Strong message

Cohort C: A message isn’t empowering just because it says the word; Best delivered by a patient

Key Takeaways: Trusted doctor is not favored, suggest replacing with “a healthcare provider you trust” or just “a healthcare provider.”

MESSAGE 14: If you find yourself or a loved one in the place where you need to make some serious decisions about your health, I want you to talk to a trusted doctor about clinical trials.

Cohort A: Replace doctor with HCP (not all providers are doctors); Same feedback about “trusted doctor”; “A doctor your trust” is a stronger message, careful to not imply there are negligent doctors. Maybe say “talk to YOUR doctor”, we do need to acknowledge that patients should have choice if they are not having a good experience with their current doctor; “Clinical trials” are among the things, don’t make it seem like the only thing; “Include a conversation about clinical trials”

Cohort B: Agree to use HCP not just doctor; “Talk to a trusted doctor about all of the options including clinical trials,” should be more specific: talk to your oncologist

Cohort C: The word “serious” gave some pause; You don’t need to be in a serious situation, just relevant to your care; When you get to the point in your care when you are “offered the opportunity to make decisions about your health you should talk to a trusted doctor”

Key Takeaways: See above comments about trusted doctor; This message resonated with some participants but others felt like you don’t need to be in a serious situation to talk about clinical trials, just in a relevant situation.

ADDITIONAL NOTES

Cohort A:

- Tone should be helpful
- Women doctors might be more trusted
- Black female IRB employee might be very powerful to feature in messaging.
A person to represent the committee that is responsible for safeguards

Cohort B:

- Get the facts/make an educated decision are strong messages
- Suggested adding a message about including your family in decision/family can help be your advocate
- Suggested adding a message about advocating for yourself and doing your research
- Empowered language is strong
- Making a connection to real life by featuring a new drug that was approved after a trial. Consider this for web content

Cohort C:

- Participation = Representation is catchy, easy to remember and means so much

Final Assets

The findings from the research phase influenced the development of the following assets as well as a comprehensive digital campaign which involved paid and organic social media, advertisements in targeted publications and an Instagram influencer campaign.

[Lung.org/trials-and-you](https://lung.org/trials-and-you)

This campaign landing page provides context around the campaign, explains clinical trials in detail and offers opportunities to get involved in the campaign.

Video (under 2 minutes): [A Doctor and Pastor on Clinical Trials in the Black Community](#)

Dr. Ozuru Ukoha and Pastor Willie J. Collins discuss the importance of clinical trials in the Black community in this brief video. This video marries the perspectives of a local Black Pastor and a Black lung cancer physician, two figures often trusted messengers in the Black community.

Video (under 2 minutes): [Sheena: Lung Cancer Clinical Trial Participant](#)

Lung cancer clinical trial participant, Sheena, discusses what she would share with other Black Americans newly diagnosed with lung cancer in this brief video.

Video (30 seconds): [Pastor Collins on Clinical Trials](#)

Pastor Willie J. Collins discusses the importance of clinical trials for Black Americans in this shorter video that can be disseminated more widely through paid advertising channels like social media and through PSA distribution services.

Video (30 seconds): [Dr. Ozuru Ukoha on Clinical Trials](#)

Thoracic surgeon, Dr. Ozuru Ukoha, discusses the importance of lung cancer clinical trials for Black Americans in this shorter video that can be disseminated more widely through paid advertising channels like social media and through PSA distribution services.

Video (30 seconds): [Sheena on Clinical Trials](#)

Sheena, a lung cancer clinical trial participant, shares her decision to participate in a clinical trial in this shorter video that can be disseminated more widely through paid advertising channels like social media and through PSA distribution services.

Campaign Feedback Survey

Prepared for the American Lung Association by the Research & Evaluation Group at Public Health Management Corporation (PHMC)

Respondents were randomly assigned to view different sets of campaign products before answering identical survey questions as noted below:

33% of respondents viewed:

- Video 1 (A Doctor and Pastor on Clinical Trials in the Black Community)
- Video 3 (Pastor Collins on Clinical Trials)

33% of respondents viewed:

- Video 2 (Sheena: Lung Cancer Clinical Trial Participant)
- Video 4 (Dr. Ozuru Ukoha on Clinical Trials)

34% of respondents viewed:

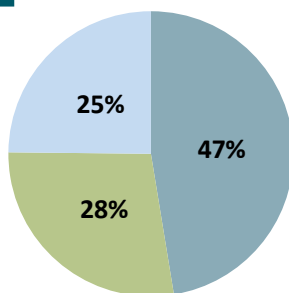
- Video 5 (Sheena on Clinical Trials)
- Campaign web page

This report presents cumulative data across all 310 respondents. Importantly, all respondents identified as Black or African-American.

Clinical Trials Campaign Feedback Survey

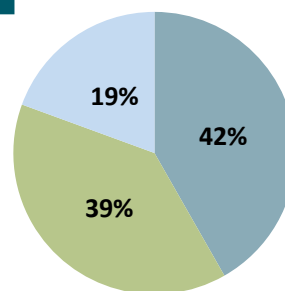
Summary Report: Findings from 310 respondents

Location



- Chicago, IL
- Houston, TX
- Philadelphia, PA

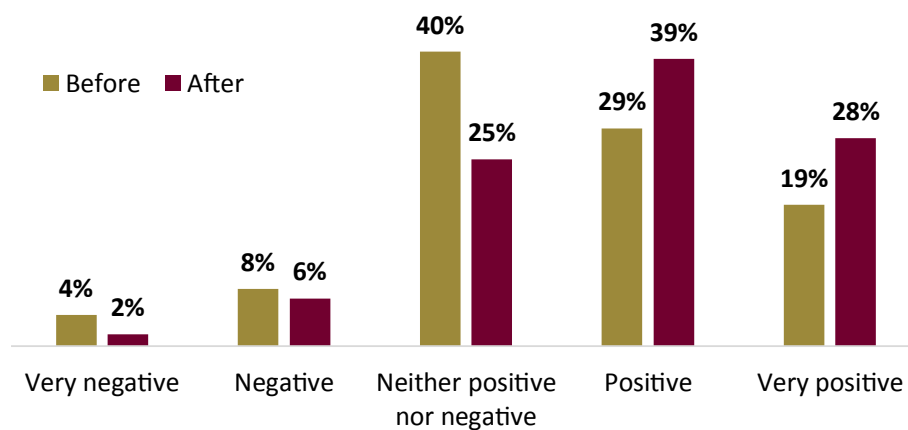
Age



- 18-35 years old
- 36-55 years old
- 56+ years old

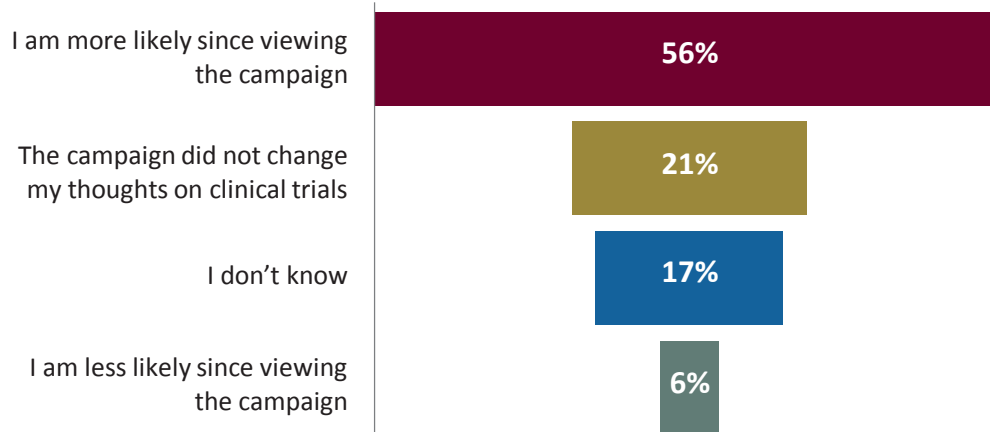
Effects of the Campaign

Attitudes towards participating in a clinical trial. Before viewing the campaign, a little under half of the respondents had neither negative nor positive attitudes towards clinical trial participation. After viewing the campaign, only a quarter of respondents had neither negative nor positive attitudes, and a greater percentage of respondents indicated positive and very positive attitudes. Overall, the campaign successfully improved respondents' attitudes towards participating in a clinical trial.



Effects of the Campaign (continued)

Likelihood of considering a clinical trial as a treatment option. After viewing the campaign, respondents were asked how likely they are to consider a clinical trial as a treatment option for themselves or a loved one if they were diagnosed with cancer. More than half of the respondents expressed a greater likelihood of considering a clinical trial as a treatment option after viewing the campaign.



Call to action. Respondents were asked whether viewing the campaign encouraged them to take action now or in the future. The campaign motivated over one-third of respondents to talk to a friend, loved one, or health care provider about clinical trials and do more research on clinical trials. One-third of respondents also expressed motivation to visit American Lung Association web pages. Only 12% of respondents said they would not take action.



Campaign Message

Learning something new after viewing the campaign. An overwhelming 85% of respondents indicated they had learned something new after viewing the campaign.

Sharing the campaign message. When asked if they would share the campaign message with friends, family, and others either now or in the future, 61% of respondents said they were likely and very likely to. Around 12% of respondents were unlikely or very unlikely, and 27% were neither likely nor unlikely.

Communicating the importance of clinical trials. 77% of respondents indicated that the campaign clearly communicated information about the importance of clinical trials. Only 10% of respondents believed the campaign did not clearly communicate this information.

“I learned that it can be possible for myself as a black male to receive better medical care as a result of participating in clinical trials.”

“I learned that there was active interest for Black people to take part in clinical trials; I knew all about racism in the medical field.”

“That they have clinical trials that you can get treatment and the research data is used for the purpose of helping other in the future.”

“I learned that blacks could benefit from participation in lung cancer clinical trials. It not only helps them but also helps doctors to learn what works for them. It might also be the only way for them to get access to cutting edge treatment. I also learned that everyone in these clinical trials get treatment and not a placebo like in other trials.”

“I learned that African Americans typically do not participate in clinical trials; therefore, there is not a lot of research/answers available for African Americans.”

“To look more into American Lung Association and educate myself on this because I don’t know much about it.”

“African American are needed to participate in clinical trials so that more ethnic specific outcomes with treatment can be discovered.”

“That trials can make a difference in the community.”

What Respondents Liked Most

Representative

- “The people in the video looked like me.”
- “It’s made for people with my background.”
- “I liked the outreach to the Black community; it’s not that common.”
- “I liked that there were people of color encouraging other people of color to do clinical trials.”
- “I liked that it featured such a strong sense of diversity amongst participants and normalcy.”
- “I like that it talked about race discrimination in medical care.”

Authentic

- “It was very informative, it made me feel like I have someone who really cares.”
- “It was authentic and heartfelt.”
- “How honest the people in the ad were.”
- “I like that they had a doctor delivering the message instead of an actor.”
- “Real doctors real people talking to the community about what’s needed to save our lives.”

Informative

- “How easy it was to understand and get the message of what it was all about.”
- “The campaign is on point. Very educational. Something that I was not aware of or have never thought about.”
- “The fact that it outlined the advantages of clinical trials.”
- “I like that it was very informative in the short time frame. If I was looking for a clinical trial, I have foundation information to do more research.”

Encouraging

- “That it encourages African American in their health choices.”
- “Direct message exploring the problem and suggesting a game plan for the solution.”
- “It’s trying to reassure an ethnicity that is always skeptical given past history in trials.”
- “I am so glad to see the video on clinical trials, and will ask my doctor about them.”
- “It makes me want to look more into it and help others!”

Respondents’ Suggestions For Improvement

- “Not sure, what to ask the doctor and if it’s available for all insurances.”
- “Perhaps some stats regarding participation and mortality rates vs other populations.”
- “I think they could have showed how much clinical trials help by posting numbers and graphs.”
- “More life stories from actual patients.”
- “More insight on benefits of the trials.”
- “I thought the participants talked too fast or maybe the motion of the video could’ve been slowed down more.”
- “Showing more of the research being done.”
- “More specialist talking about how they make things easier for you.”
- “Showing more diverse people actually participating in trials and discussing their outcomes.”
- “Testimonials from past participants and long term results and/or progress.”
- “A real story from a patient and his/her health care provider.”

Conclusion

Improving clinical trial enrollment is key to ensuring better health outcomes for Black Americans with lung cancer. Communication about a topic that may bring up fear and uncertainty in the target population takes a thoughtful and nuanced approach. The findings discussed in this paper are a jumping off point for communicators and health educators, however more research needs to be done. No racial or ethnic group is homogenous, and it is important to note there is always room for deeper analysis regarding thoughts, attitudes and beliefs. For example, the focus groups revealed the generational divide should be a factor when considering additional communications for this campaign, noting specifically how different generations engage in messaging about social justice and health equity. The campaign also focused on three cities, Philadelphia, Chicago and Houston, large metropolitan areas that have many things in common, but whose residents differ in many ways. As the American Lung Association and other advocates consider further messaging on this topic, it is advisable to consider refining the target population and further customize the message based on existing and future research.

Together, stakeholders can improve health outcomes for Black Americans. Using the guidance provided in this document, we can increase the amount of quality lung cancer clinical trial health education materials and shift the conversation from fear-based to fact-based.

Acknowledgements

The American Lung Association graciously acknowledges Daniel J. Woytowich, DrPH Candidate, MPH, MS, XunXuan Chen, the Research & Evaluation Group at Public Health Management Corporation (PHMC) and the many focus group participants, interviewees, and advisors for their contributions to this project.

Funding for this initiative was generously supported by AstraZeneca, Bristol Myers Squibb, Genentech and Merck.

This document was prepared by Carly Ornstein, MPH CHES.

Appendix

Full listing and findings from Literature Review.

Alhaji, M., Bauerle Bass, S., Nicholson, A., Washington, A., Maurer, L., Geynisman, D. M., & Fleischer, L. (2020). Comparing perceptions and decisional conflict towards participation in cancer clinical trials among African American patients who have and have not participated. *Journal of Cancer Education*, 2020, 1-10.

<https://doi.org/10.1007/s13187-020-01827-w>

A total of 41 Black cancer patients completed a survey on their perceptions of clinical trials. Patients who had never participated in a clinical trial reported fears of the trial making them sicker, concerns about insurance coverage, never having been asked to participate in a trial, and being too upset about their cancer diagnosis to think about being part of a trial. Interestingly, participants who had participated in a clinical trial were three times more likely to have a smart phone. Contrary to other research, this study found no difference between the two groups on beliefs that they would be a “guinea pig” if they participated in a trial, and distrust in researchers or the medical community. The doctor-patient relationship was important in decision-making; participants who had took part in a clinical trial believed that their doctor gave them enough information to make a decision on whether to participate, and were more likely to follow their doctor’s advice if they recommended trial participation.

Awidi, M., & Al Hadidi, S. (2021). Participation of Black Americans in cancer clinical trials: Current challenges and proposed solutions. *Oncology Practice*, 17(5), 265-271.

<https://ascopubs.org/doi/pdf/10.1200/OP.21.00001>

The authors reviewed existing literature to identify factors related to Black Americans’ clinical trial participation and propose potential solutions. Barriers cited include, but are not limited to: strict inclusion and exclusion criteria, biological differences in laboratory values due to race, fears of unequal treatment, financial constraints, and beliefs that informed consent forms primarily protect hospitals and researchers. Many cancer clinical trials are industry-sponsored, so researchers may not be required to regulations on the inclusion of women and participants from minority groups.

Cunningham-Erves, J., Barajas, C., Mayo-Gamble, T. L., McAfee, C. R., Hull, P. A., Sanderson, M., Canedo, J., Beard, K., & Wilkins, C. H. (2020). Formative research to design a culturally-appropriate cancer clinical trial education program to increase participation of African American and Latino communities. *BMC Public Health*, 20(1), 840.

<https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-020-08939-4>

The authors developed a culturally-appropriated, single-session, in-person educational program using peripheral, evidential, linguistic, and sociocultural strategies to increase Black and Latinx patients' participation in cancer clinical trials and biospecimen donation. When receiving feedback on the program, both groups expressed a desire for personal testimonials on trial participation, images and illustrations that did not reflect a specific population, and information sheets on how to enroll in clinical trials. Black participants identified barriers to trial participation such as distrust in providers and researchers, disbelief in the cancer disparity, limited access to clinical trials and healthcare, and fear of research procedures.

Davis, T. C., Arnold, C. L., Mills, G., & Miele, L. (2019). A qualitative study exploring barriers and facilitators of enrolling underrepresented populations in clinical trials and biobanking. *Frontiers in Cell and Developmental Biology*, 7, 74.

<https://doi.org/10.3389/fcell.2019.00074>

The authors conducted focus groups with 103 healthcare providers, patients, and community members. Approximately 79% of the patients and community partners were Black. Black participants strongly encouraged information about clinical trials to incorporate all races and ethnicities; targeting one specific group makes it appear suspicious. Some Black participants reported not feeling close to their or their family's physicians and expressed interest in participating in clinical trials but weren't certain how to find trials or enroll.

Duma, N., Aguilera, J. V., Paludo, J., Haddox, C. L., Velez, M. G., Wang, Y., Leventakos, K., Hubbard, J. M., Mansfield, A. S., Go, R. S., & Adjei, A. A. (2018). Representation of minorities and women in oncology clinical trials: Review of the past 14 years. *Journal of Oncology Practice*, 14(1), e1-e10.

<https://ascopubs.org/doi/abs/10.1200/JOP.2017.025288>

The authors reviewed the enrollment of minorities and female patients in breast, colorectal, lung, pancreas, prostate, renal cell carcinoma, and melanoma clinical trials registered on ClinicalTrials.gov from 2003 to 2016. Across all 310 trials that reported race and ethnicity, approximately 5.9% of patients were Black. For lung cancer trials specifically, Black participants comprised 5.4% of all participants and only 1.5% of all Black patients with lung cancer. From 2011 to 2015, there has been a decline in the percentage of Black participants in lung cancer trials. Interestingly, across the seven types of cancer trials, Black patients were less likely to participate in industry-sponsored trials than NIH/NCI-, academic-, and foundation-sponsored trials. One limitation is the use of data from trials that have been registered and listed as completed on ClinicalTrials.gov; the findings may not be representative of trials that have not been registered and/or marked as completed on ClinicalTrials.gov.

Hamel, L. M., Penner, L. A., Albrecht, T. L., Heath, E., Gwede, C. K., & Eggly, S. (2016). Barriers to clinical trial enrollment in racial and ethnic minority patients with cancer. *Cancer Control*, 22(4), 327-337. <https://doi.org/10.1177/107327481602300404>

This paper explores system, individual, and interpersonal level factors that contribute to disparities in clinical trials. Prior research suggests that physicians are hesitant to discuss clinical trials with their Black patients because of perceptions that Black patients mistrust the medical and research communities, and implicit biases that Black patients are not good candidates for clinical trials. Black patients have expressed interest in participating in clinical trials but often don't because of lack of awareness of clinical trials. When physicians and Black patients discuss clinical trials, the discussions tend to be shorter than those with White patients.

Pang, H. H., Wang, Z., Stinchcombe, T. E., Wong, M. L., Cheng, P., Kishor Ganti, A., Sargent, D. J., Zhang, Y., Hu, C., Mandrekar, S. J., Redman, M. W., Manola, J. B., Schilsky, R. L., Cohen, H. J., Bradley, J. D., Adjei, A. A., Gandara, D., Ramalingam, S. S., & Vokes, E. E. (2016). Enrollment trends and disparity among patients with lung cancer in national clinical trials, 1990 to 2012. <https://ascopubs.org/doi/10.1200/JCO.2016.67.7088>

The authors examined data from 23,006 patients across 210 NCI-sponsored lung cancer clinical trials from 1990 to 2012. Throughout this period, Black patients were consistently underrepresented and there were minimal improvement in enrollment rates over time.

Pariera, K. L., Murphy, S. T., Meng, J., & McLaughlin, M. L. (2017). Exploring willingness to participate in clinical trials by ethnicity. *Journal of Racial and Ethnic Health Disparities*, 4(4), 763-769. <https://doi.org/10.1007/s40615-016-0280-6>

A random sample of 173 Black individuals completed a survey on their attitudes towards clinical trials. Compared to White respondents, Black respondents indicated greater mistrust of doctors, greater acceptance of alternative and complementary medicine for cancer treatment, greater likelihood of finding information about trials from their church, and lesser likelihood of participating if they were not told which condition/group they were a part of. Interestingly, Black respondents were more likely than White respondents to participate in a trial if the doctor would profit from the drugs being tested. Respondents across all races and ethnicities preferred finding information on trials from doctors, internet searches, and organizations dedicated to cancers.

Rivers, D. A., Pal, T., Vadaparampil, S. T., Adams, L. A., Dash-Pitts, L., & Quinn, G. P. (2019). A community-academic partnership to explore informational needs of African American women as a primer for cancer clinical trial recruitment. *Ethnicity and Health, 24*(6), 679-693. <https://doi.org/10.1080/13557858.2017.1367762>

A total of 42 Black women without cancer but with a family history of cancer participated in focus groups to provide feedback on a video that was designed to address concerns about cancer clinical trials for newly diagnosed cancer patients. The focus groups revealed themes such as fear of abuse and mistreatment based on past historical events, concerns that researchers prioritize research instead of participants' well-being, fears of unknown outcomes and side effects, the importance of researchers' credentials and the presence of a medical professional to inform them of the clinical trial and answer questions, lack of awareness of available clinical trials, and the importance of involving family in decision-making. Participants suggested increasing advertisements in community settings, specifically at local churches, and recommended culturally-relevant content and additional decision-making tools using plain language.

Robinson, B. N., Newman, A. F., Wallington, S. F., & Swain, S. M. (2016). Focus on you: Cancer clinical trials perspectives. *Contemporary Clinical Trials Communications, 4*, 170-178. <https://doi.org/10.1016/j.conctc.2016.09.004>

Focus groups were conducted with 12 Black patients with breast cancer and their relatives/caregivers, healthcare providers, and religious leaders to collect participants' thoughts on Black women's participation in breast cancer clinical trials. Themes included: the importance of the patient's relationship with their doctor, mistrust in clinical research based on historical abuses, beliefs of unequal treatment and being treated as a "guinea pig" and designing inclusion and exclusion criteria that account for co-morbidities. Participant recommendations included: connecting patients with other participants to discuss their clinical trial experiences, distributing flyers and literature in social workers' offices and churches, using the church to increase clinical trial education, and having the physician involved early in recruiting patients.

Sprague Martinez, L., Freeman, E. R., & Winkfield, K. M. (2017). Perceptions of cancer care and clinical trials in the Black community: Implications for care coordination between oncology and primary care teams. *The Oncologist, 22*(9), 1094-1101. <https://doi.org/10.1634/theoncologist.2017-0122>

Key informant interviews were conducted with health care providers, patient advocates, and community organizers. Key informants identified the following barriers to clinical trial participation among Black patients: negative perceptions of clinical trials (older patients in particular still think about the Tuskegee study), low socioeconomic status, a lack of information on how to get involved in and prepared for clinical trials, and lack of public transportation or access to a car.

Focus groups were conducted with Black cancer survivors and family members. Overall, participants associated the phrase “clinical trial” with “experiments,” “guinea pigs,” “exploitation,” and historical exploitation. One participant was quoted saying that people get paid to do the clinical trials but no money or information is shared with the community. Several participants expressed distrust in cancer care providers due to negative experiences but conveyed trust in their primary care physicians, to whom they would return to ask for advice. Some participants were too overwhelmed or upset by their cancer diagnosis to consider participating in a clinical trial, and some were concerned about the effect of trial participation on their families.

Unger, J. M., Hershman, D. L., Osarogiagbon, R. U., Gothwal, A., Anand, S., Dasari, A., Overman, M., Loree, J. M., & Raghav, K. (2020). Representativeness of Black patients in cancer clinical trials sponsored by the National Cancer Institute compared with pharmaceutical companies. *JNCI Cancer Spectrum*, 4(4), pk11034. <https://doi.org/10.1093/jncics/pkaa034>

Data were examined from 46,313 patients across 85 pharmaceutical-sponsored trials and 47,512 patients across 273 SWOG trials from 2008 to 2018 for 15 different types of cancer. Black patients comprised 2.9% of the pharmaceutical-sponsored trials and 9.0% of the SWOG trials. For lung cancer trials specifically, 26.0% and 8.2% of pharmaceutical and SWOG trial, respectively, were Black patients.