



**Improving Lung Cancer Clinical Trial Enrollment Among
Hispanic Individuals Living in the United States:
Guidance for Developing Health Promotion Materials**

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Executive Summary

News of lung cancer treatment and early detection advances have been making headlines at a steady clip over the past decade. Types of lung cancer previously thought of as “undruggable” are now treatable, and researchers have discovered ways to utilize a variety of agents to tackle the number one cause of cancer death in the United States. Through advances in screening, lung cancer can be caught at earlier stages and often treated with state-of-the-art surgical techniques performed minimally invasively. The excitement around treating this disease is often palpable. However, behind these exciting discoveries is a hard truth about cancer care in America: Disparities persist, and too often, historically underrepresented communities do not receive the highest level of care available, which results in poorer health outcomes.

This is the case for one of the fastest growing populations in the United States: Hispanic individuals. Lung cancer stakeholders have called attention to many of the disparities faced by Hispanic individuals, including underrepresentation in clinical research. Advocates have worked tirelessly, but more needs to be done on a greater scale. Everyone has a role to play.

The American Lung Association, one of the nation’s oldest health organizations, is committed to reducing health disparities, including those faced by Hispanic individuals. One example is through educational campaigns like the [Awareness Trust and Action \(ATA\)](#) project. This project began in 2021 and focused on improving clinical trial enrollment among Black individuals living in the United States, another population historically underrepresented in clinical research.

Following the success of the initial ATA project, the Lung Association expanded the project’s scope to reach the Hispanic population.

As with the first iteration of ATA, the current campaign is heavily informed by the target audience, with a robust research phase preceding the development of key messages and assets. The research phase included a literature review, landscape survey, stakeholder interviews and focus groups, with each activity informing the next.

The research revealed many interesting thoughts and behaviors, and several key themes emerged, which should be strongly considered by stakeholders when planning communication to Hispanic individuals about clinical trials.

Firstly, family and community are often a touchstone of Hispanic culture, a sentiment that emerged especially clearly in the landscape survey and stakeholder interviews. Hispanic individuals may be motivated to act on an issue if it means helping their family and they are likely to seek input from their family when making a large health decision, like participating in a clinical trial.

Next, physicians tend to be trusted within the Hispanic community. However, there is a general mistrust of the medical system, and in particular, skepticism about pharmaceutical companies. Trusted physicians may make great spokespeople but should be prepared to confront misconceptions about clinical trials and discuss the benefits to the patient, the safety mechanisms in place and the role of pharmaceutical companies in the process.

The term “Hispanic” refers to a person with ancestry from a country whose primary language is Spanish, whereas “Latino” and its variations refer to a person with origins from anywhere in Latin America and the Caribbean. Because the term Hispanic is tied to language and there was an intent to create Spanish-language resources for this iteration, the term “Hispanic” was used throughout the project. However, because of the overlap of terms in epidemiological reporting, “Latino” and its variations may be used when citing statistics throughout this document. Additionally, varying terms may appear when citing direct quotes.

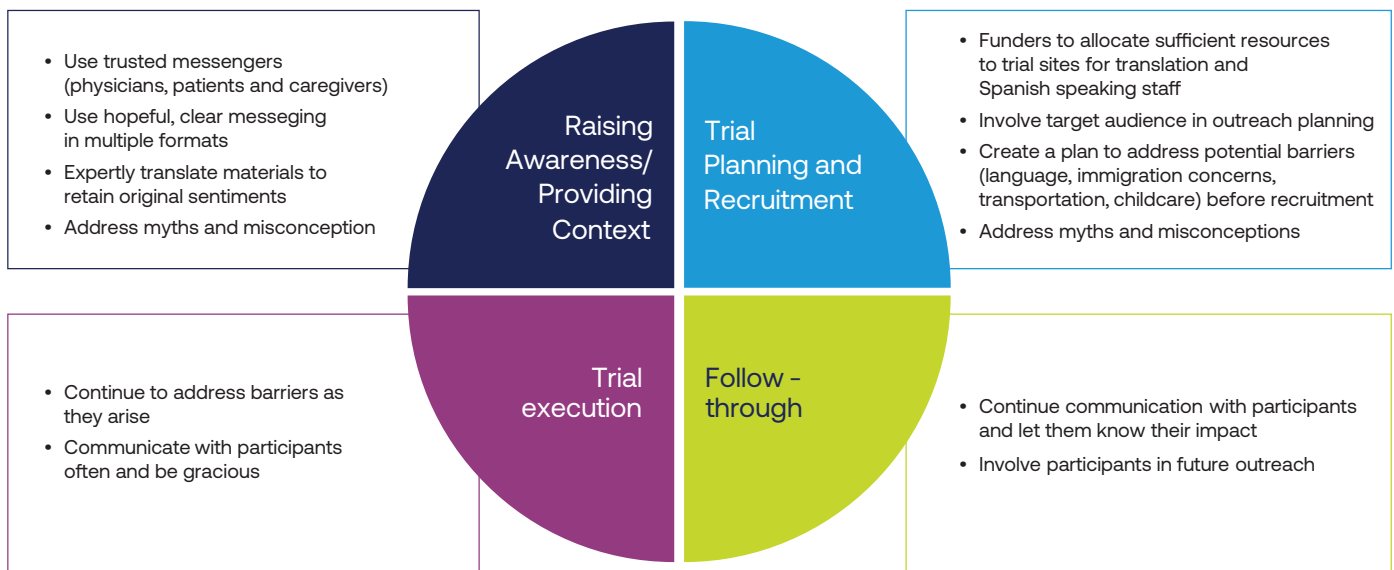
Stakeholders should also give careful thought to translation. While the landscape survey revealed the target audience’s general propensity toward consuming healthcare materials in English, the stakeholder interviews and focus groups generated interesting discussions about the importance of the availability of Spanish-language materials. Spanish-language materials should be readily available and expertly translated from English, ensuring accuracy and overall sentiment is retained. Study sites should have a Spanish-speaking staff member available to answer questions about study protocol as clinical trial enrollment language can be challenging for a lay person to understand.

Language may not be the only barrier to trial participation for Hispanic individuals. For instance, participating in a trial can be time consuming, creating challenges with securing time off work and childcare. Concerns about immigration status may also deter Hispanic individuals from participation.

Communication can help reduce some barriers related to fear. A recurring theme in the data was the importance of communication to the participants about the trial, including how an individual’s participation is making an impact. Expressions of gratitude and involving participants as partners in the research may help thwart participant concerns of being a “lab rat” or an anonymous subject solely benefiting trial funders.

Improving clinical trial enrollment is a multi-faceted issue. Interventions cannot exist in a vacuum if stakeholders want to change the trial landscape. The graphic below (Chart A) shows action items that arose from the project’s research phase and the corresponding phase of the clinical trial recruitment process. Stakeholders should consider where they enter this process and their role in executing the corresponding action items.

Actions to Improve Clinical Trial Enrollment (Chart A)



Building on the research findings, the Lung Association released several assets to raise awareness of clinical trials and provide important context about trials among the target audience of Hispanic individuals. Assets included four public service announcement-style videos as well as informative campaign landing pages available in English and Spanish available at Lung.org/clinical-trials-and-you and Lung.org/ensayos-clinicos-y-usted.

A campaign feedback survey among the target audience revealed the assets improved attitudes toward clinical trials and increased knowledge about clinical trials. Assets were well-received, and the majority of participants indicated they would share the assets with their community.

Future campaigns with similar goals to *ATA*, should consider the research discussed in this document when planning creation and distribution of future assets. Considering the high levels of trust in physicians and the importance of family in the Hispanic community, future campaigns may want to feature a physician spokesperson and more images/stories about family.

All patients with lung cancer deserve the highest standard of care available to them, but sadly this is not always the reality. Clinical research is imperative to not only the discovery of new lung cancer interventions, but to the lung cancer armamentarium. To move the needle and ensure Hispanic individuals are included in clinical research, stakeholders need to reduce language and access barriers in a comprehensive and thoughtful way while involving the target audience in clinical trial outreach activities.

Simply translating materials from English is insufficient. Entities that provide education about clinical trials to Hispanic individuals, like healthcare workers and public health and patient advocacy organizations, should recognize that while hesitancy and misconceptions exist within the community, there is also an interest and willingness to learn more. When clear, hopeful and accessible information is presented to the target audience through a trusted messenger, one can expect the information to be favorably received. Representation matters, and a shift to increased thoughtfulness from all stakeholders when serving the Hispanic community means that the clinical trial enrollment landscape will also shift, and with it, the lung cancer community will be one step closer to reducing health disparities.

Background

In 2021, the American Lung Association launched *Awareness Trust and Action (ATA)*, a project aimed at improving awareness and trust of lung cancer clinical trials among Black individuals living in the United States while encouraging this population to act by talking with their doctor about clinical trials. The education campaign was successful and well-received by the community and the following year, the Lung Association created additional assets and further promoted campaign materials.

Given the success of the initial campaign, the Lung Association proposed creating a version of *ATA* that focused on another population often underrepresented in clinical research in the United States: Hispanic individuals. Lung cancer is the number one cause of cancer-related death in the United States. According to data from the Lung Association's 2024 State of Lung Cancer Report, Latino individuals with lung cancer were 17% less likely to be diagnosed early and 30% more likely to not receive any treatment compared to white individuals in America.¹

While there has been progress in the early detection and treatment of the disease in recent years, this progress has not been shared equally, and lung cancer disparities continue to impact the Hispanic community.

Lung cancer research is moving at a rapid pace, and clinical trials are critical to advancing promising lung cancer treatments. However, only 1% of the clinical trial population is represented by Hispanic individuals.² A 2024 study used data from [ClinicalTrials.gov](https://clinicaltrials.gov) to evaluate the distribution of racial/ethnic minority enrollment in non-small cell lung cancer (NSCLC) clinical trials. Of the 28,540 trial participants, 79.6% were white, 3% Black, 10.4% Asian or Pacific Islander and only 3.4% Hispanic/Latino.³

The Hispanic population remains underrepresented in clinical research and should benefit from the cutting-edge therapies clinical trials may offer. Clinical trials are sometimes the most appropriate **treatment option** for a lung cancer patient. Additionally, it is important for researchers to learn how different types of people react to new treatments or interventions. This creates a more accurate understanding of how interventions will impact a larger population.

Low lung cancer clinical trial enrollment among Hispanic individuals in the United States is a complex topic that will take a multi-pronged approach to address.

Through the most recent *ATA* campaign, the Lung Association released several educational assets, including four PSA-style videos and an informative webpage (available in English and Spanish). The assets were promoted to Hispanic individuals and their families/caregivers nationwide, with a particular focus on the following metropolitan areas that have the highest lung cancer incidence and mortality rates among Hispanic individuals in the United States:

- Port St. Lucie, FL
- Fort Lauderdale/Miami, FL
- Albuquerque/Santa Fe, NM
- Las Vegas, NV

1 American Lung Association. (2024). State of Lung Cancer | Racial and Ethnic Disparities. Lung.org. <https://www.lung.org/research/state-of-lung-cancer/racial-and-ethnic-disparities>

2 American Lung Association. (2024). Lung Cancer and Clinical Trials in the Hispanic and Latino Populations. Lung.org. <https://www.lung.org/lung-health-diseases/lung-disease-lookup/lung-cancer/basics/lung-cancer-research/clinical-trials-hispanic-latino>

3 Wheeler, M., Karanth, S., Divaker, J., Yoon, H.-S., Yang, J. J., Ratcliffe, M., Blair, M., Mehta, H. J., Rackauskas, M., & Braithwaite, D. (2024). Participation in Non-small Cell Lung Cancer Clinical Trials in the United States by Race/Ethnicity. *Clinical Lung Cancer*. <https://doi.org/10.1016/j.clcc.2024.09.009>

Prior to asset development, the Lung Association and its partners conducted a robust research phase to ensure campaign key messages were salient, culturally competent and informed by the target audience. The research phase followed the below 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.

Literature Review → Landscape Survey → Key Informant Interviews → Focus Groups

The Lung Association's ATA campaign strives to empower individuals to speak with their healthcare providers about treatment options and make informed decisions about participating in clinical trials. The findings from this campaign aim to inform entities drafting future communications about clinical trials to improve clinical trial recruitment rates among Hispanic individuals living in the United States.

Research Methods

Literature Review

The Research & Evaluation Group at Public Health Management Corporation (PHMC) prepared a literature review for this project. A complete list of the research reviewed is available in the Appendix. The literature review conducted by PHMC provides a snapshot of some of the key issues to consider when addressing clinical trial enrollment among Hispanic individuals living in the United States. Below is a high-level summary of the research.

Summary

The collective literature describes the underrepresentation of this population in clinical research. Hispanics are the largest minority group in the United States, and disparities in the diagnosis and clinical outcomes of Hispanic patients with lung cancer compared with non-Hispanic white patients are well documented. The Hispanic population faces disadvantages related to social determinants of health including access to care and health insurance and immigration issues. Moreover, there are also genetic and biological differences that need to be considered.⁴

Lung cancer treatment has evolved over the past decade with major advances in immunotherapy and targeted therapies. However, Hispanic individuals may not be accessing these treatments. Therefore, it may be challenging for researchers to understand how this population responds to certain lung cancer medications. Data on immunotherapy clinical outcomes in non-small cell lung cancer (NSCLC) for Hispanic individuals is very scarce. Most of the registration trials for these medications were done in the United States and Europe, and enrolled a minimal number of Hispanic individuals, if any. More data is needed regarding molecular testing and access to targeted and immunotherapy among Hispanics in the United States and abroad. Lung cancer treatment disparities and outcomes will not improve unless more Hispanic individuals are enrolled in clinical trials and if trials are performed in areas where Hispanic people live.³

The literature also examines potential barriers for consideration in messaging about clinical trials including discussing the benefits of participation for patients versus the benefits for researchers, creating culturally appropriate materials (including ensuring materials are available in Spanish) and understanding concerns about immigration status.^{5,6} Additionally, Hispanic individuals may experience more physical and emotional health-related barriers to participation in clinical research, which should be considered when designing trials.⁷

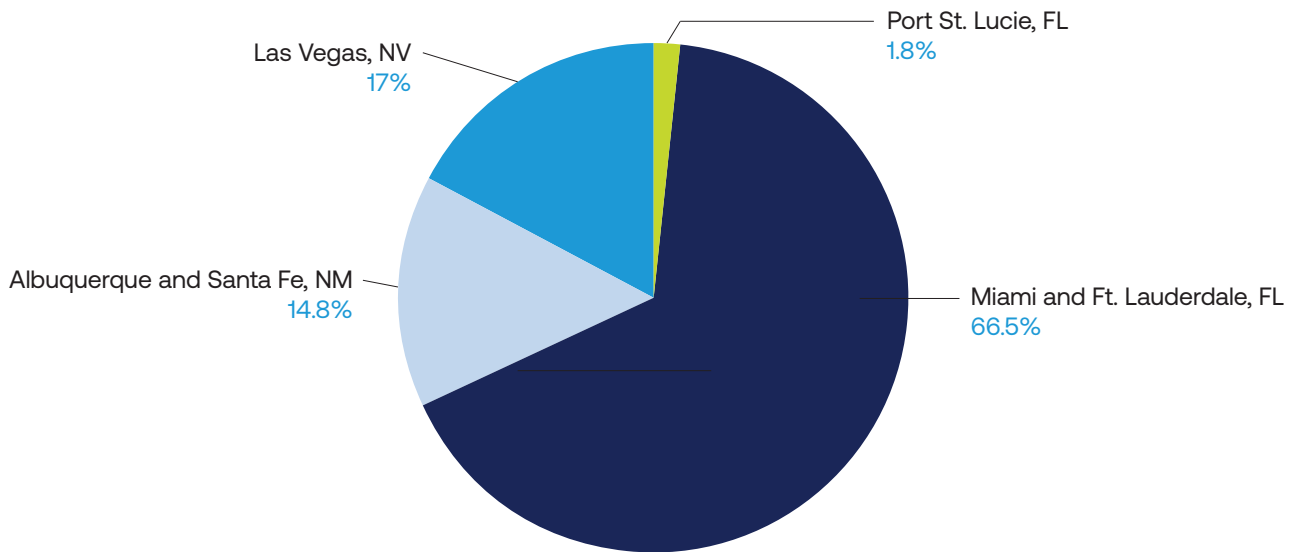
The findings from this literature review informed the future qualitative research methods used, as discussed below.

Landscape Survey

The Research & Evaluation Group at Public Health Management Corporation (PHMC) worked with the American Lung Association to create an online landscape survey. The survey gathered information about attitudes and perceptions of clinical trials, as well as learning preferences of 400 Hispanic individuals residing in the following metropolitan areas in the United States (Chart B):

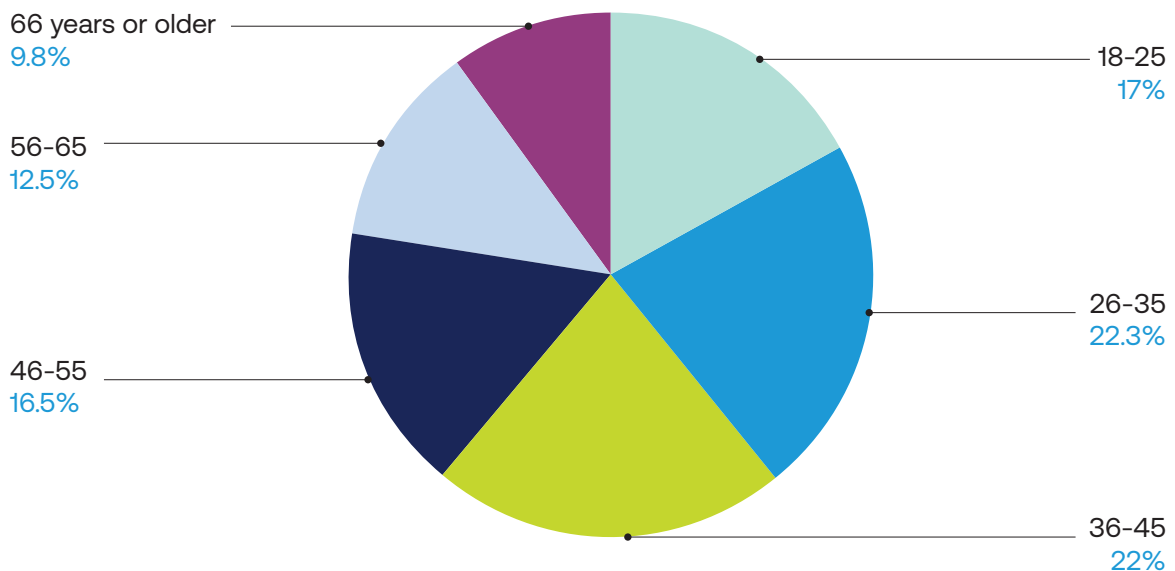
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- 4 Raez, L. E., Cardona, A. F., Lopes, G., & Arrieta, O. (2022). Challenges in Genetic Testing and Treatment Outcomes Among Hispanics With Lung Cancer. *JCO Oncology Practice*, 18(5), 374–377. <https://doi.org/10.1200/op.22.00096>
 - 5 Kaplan, C. P., Nápoles, A. M., Narine, S., Gregorich, S., Livaudais-Toman, J., Nguyen, T., Leykin, Y., Roach, M., & Small, E. J. (2015). Knowledge and attitudes regarding clinical trials and willingness to participate among prostate cancer patients. *Contemporary Clinical Trials*, 45, 443–448. <https://doi.org/10.1016/j.cct.2015.09.023>
 - 6 Lindberg, N. M., Gutierrez, A. M., Mittendorf, K. F., Ramos, M. A., Anguiano, B., Angelo, F., & Joseph, G. (2021). Creating accessible Spanish language materials for Clinical Sequencing Evidence-Generating Research consortium genomic projects: challenges and lessons learned. *Personalized Medicine*, 18(5), 441–454. <https://doi.org/10.2217/pme-2020-0075>
 - 7 Samuel, C. A., Mbah, O. M., Elkins, W., Pinheiro, L. C., Szymeczek, M. A., Padilla, N., Walker, J. S., & CorbieSmith, G. (2020). a systematic review of quality of life in Latino cancer survivors in the USA. *Quality of Life Research*, 29(10), 2615–2630. JSTOR. <https://link.springer.com/article/10.1007/s11136-020-02527-0>

Geographic Areas of Respondents (Chart B)



The online landscape survey was distributed by Alchemer to paid panel respondents, consisted of closed and open-ended questions and lasted approximately 7–10 minutes. Of the respondents, 53.4% identified as female and 44.8% identified as male. The remaining participants identified as transgender, nonbinary or chose not to answer. Below is the age breakdown of respondents (Chart C).

Ages of Respondents (Chart C)



Language Preferences:

All respondents identified as Hispanic and 98.5% of respondents indicated they speak Spanish, with 69.6% of respondents noting they speak Spanish “Very well”. However, when asked “In which language do you prefer to receive most of your health information?”, only 10.8% answered “Mostly or Only Spanish”. **Respondents across all age groups indicated a preference for health information in English, or mostly English, except participants ages 36–45.** Respondents 36–45 years of age exhibited a more even distribution between only English (33%), mostly English (19.3%) and equally English and Spanish (33%).

Respondents from Las Vegas (60.3%) and Albuquerque (64.4%) indicated a strong preference to receive health-related information in English-only. Respondents from the Fort Lauderdale/Miami metro areas indicated a slight preference for both English and Spanish materials (35%) versus only English (27.8%) or mostly English (21.8%). The small sample size of respondents from Port St. Lucie were mostly divided between only English, mostly English and both languages.

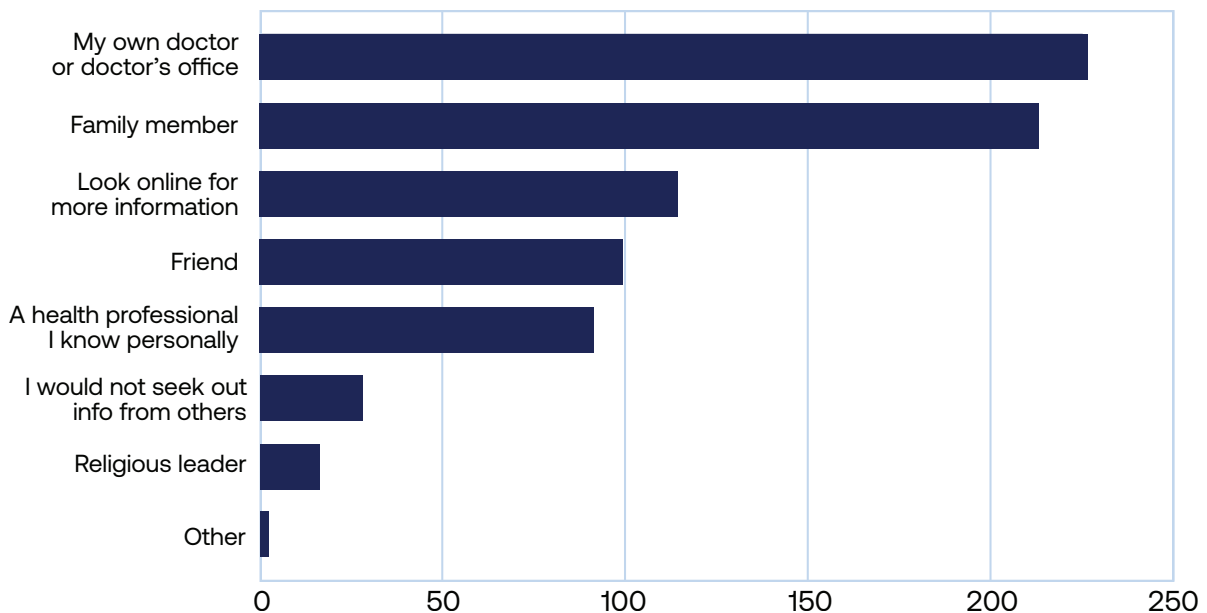
Trusted Sources of Information:

All respondents indicated they are most likely to get health information from their doctor. Followed by “from family and friends” for respondents ages 18–45 and over 65, and “from a healthcare professional I know personally” for respondents 46–65. Across all sampled geographic areas, except for respondents from Port St. Lucie, respondents indicated that they were more likely to get health information from their doctor, followed by family and friends. Among respondents from Port St. Lucie, a majority selected “a healthcare professional I know personally”.

When asked, “How much do you know what it means to participate in a clinical trial?”, most respondents said they have some knowledge (40%) or know very little (33.8%)

Respondents were asked, “If you were considering participating in a clinical trial, who would you go to for help deciding? Select all that apply.” Council from a personal doctor, as well as family members, ranked highest among respondents, as shown in the chart below (Chart D).

Who would help you decide? (Chart D)

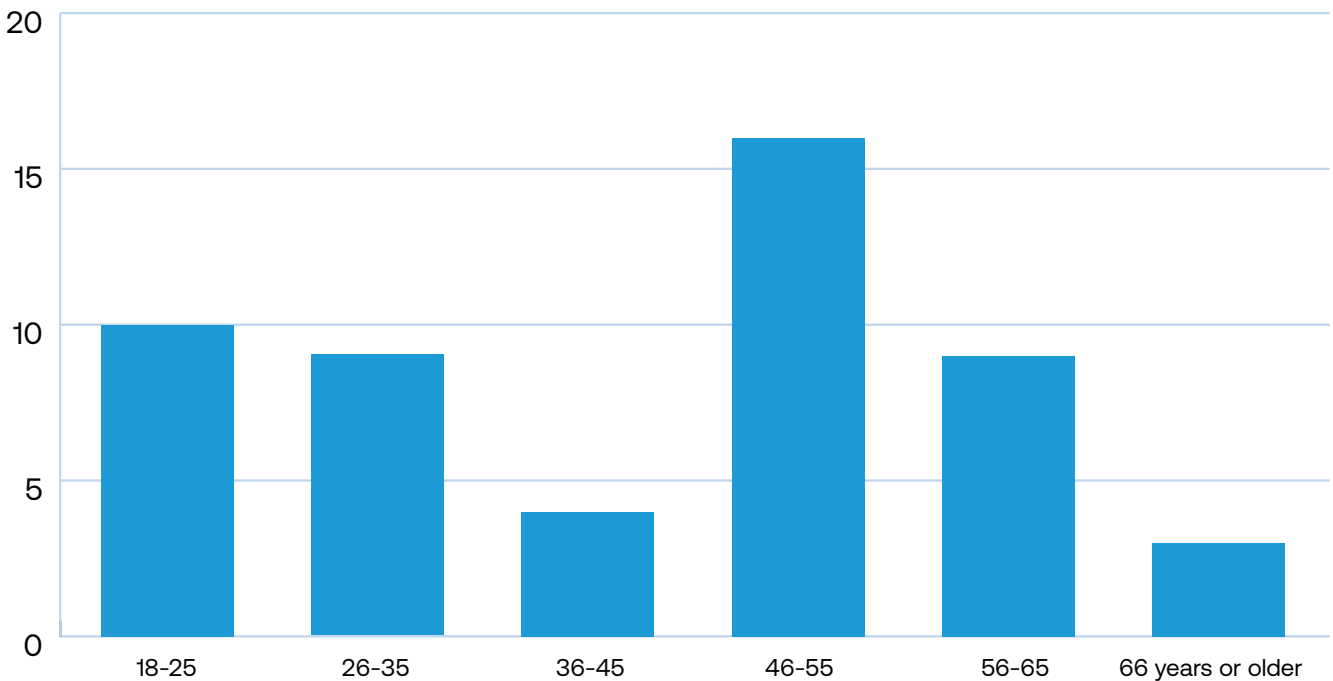


When adjusted for age, data show that most respondents ages 18-25 and 36-45 selected “family member” (70.6% and 56.8% respectively). Within the remaining age groups sampled (26-35, 46-55, 56-65 and 66 plus), the majority selected “doctors or doctor’s office” (57.3%, 62.1%, 68% and 69.2% respectively).

Apprehension:

Respondents were asked, “If you (or a loved one) were diagnosed with cancer, how likely are you to consider a clinical trial as a treatment option (or encourage your loved one to consider a clinical trial)?”. Most participants selected “very likely” (34.3%) and “likely” (37.5%). The chart below (Chart E) examines those who answered “Not sure” by age and shows that those 45-55 had the highest percentage of being unsure about clinical trial participation (24.2%).

Not Sure by Age (Chart E)



Overall Sentiments:

The survey concluded with the question: “Is there anything else that you would like to share with us about your thoughts or experience with clinical trials?”. The open-ended responses were coded into five themes:

Theme	Operational Definition	Totals Responses	Examples of Responses
Benefit	positive benefit for treatment, payment, medical science	40	<ul style="list-style-type: none"> • Is something that benefit humanity • I think the help to make better treatments in the future • Yes they pay very good most of the time and most of all the times they do the clinic trials on exactly what your going through so it helps you out the most! • I believe clinical trials are a good idea but I believe they're also could be some risk involved. • They are a great option for people without insurance. • I have made some clinical trials and everything has gone fine and I was rewarded for it. • I need a clinical trial to make some extra income. • No I always am up for doing clinical trials especially if they pay well and are for the greater good. • They are very good, apart from helping the medical community to use medications and/or procedures that can extend a patient's life!
Consider	would consider participating in a clinical trial, have participated	43	<ul style="list-style-type: none"> • Clinical trial would be a secondary option assuming that regular treatments aren't working. • I think clinical trials are interesting, and I'd like to participate in one someday. • I hope I get invited. • I would do them or at least pick and choose. Especially if it's something could possibly help me and others along the way. Also get paid to do so.

Theme	Operational Definition	Totals Responses	Examples of Responses
Don't know	need more information, wants to learn more	19	<ul style="list-style-type: none"> No I just worry about something like a trial for something as serious as Cancer. Don't know much but don't like to be fully on any pills that make you feel bad. I don't know enough. But if I were to take one I would prefer it to be the real thing.
Concern	risk, worried, negative side effect, feeling like a test subject, negative consequences, mistrust	21	<ul style="list-style-type: none"> Some clinical trials can be interesting but I think they should pay more for long lasting trials. I would be very worried about bad side effects and also feelings g like a test subject is not good for my self esteem. The sole purpose of clinical trials is to leave you with no money in your bank account. I don't like participating in clinical trials, although I don't rule out the possibility of changing my mind at some point. I would hope that they are beneficial and not just treating us like rats in a lab. Although clinical trials can be good. They can also be scary/risky for the patients involved in them.
Miscellaneous or Opinion	miscellaneous comments, opinions about the field or studies in general	33	<ul style="list-style-type: none"> Let people know the actual side effects and harm it can cause. How long it will be. Actual percentage of it working. I haven't tried one but I have a friend or two that have. Big Farma has no intention on saving the general public just ways to make more money. I think they're somewhat helpful in certain situations.

The Landscape Survey provided important insight that guided the messaging and strategy of the campaign. The findings, as well as the Literature Review, informed the development of stakeholder interview questions, as discussed below.

Stakeholder Interviews

In March 2024, Carly Ornstein, MPH, on behalf of the American Lung Association, conducted interviews with 10 stakeholders. These interviews intended to inform key campaign messages by identifying common themes regarding clinical trial enrollment among Hispanic individuals living in the United States.

Methods and Data Collection

This qualitative analysis summarizes the results gathered from 10 separate, 30-minute interviews conducted by Ornstein. These interviews followed the following general format below:

1. Project background
2. Stakeholder’s background and their personal and professional experience
3. Specific questions, which varied based on the stakeholder’s experience

All stakeholders identified as Hispanic or served the Hispanic community in a professional capacity. Stakeholders’ ages ranged from 30’s to 60’s. Below is a high-level overview of the interviewees:

Sex	Description	Location
Female	Cancer survivor and retired Chief Officer of Diversity of a cancer non-profit	Winter Garden, FL
Female	Lung cancer patient and American Lung Association volunteer	Miami, FL
Female	Lung cancer patient, translator and advocate	La Puente, CA
Female	Certified clinical research coordinator	Lemon Grove, CA
Male	Medical Director, Thoracic Oncology Program Director and American Lung Association volunteer	New York, NY
Male	Wellness Enterprise, Senior Physician Executive	Garden Grove, CA
Male	Medical Director for Quality and American Lung Association volunteer	Los Angeles, CA
Female	Physician and CEO and American Lung Association volunteer	Chicago, IL
Male	EVP of clinical trial software company	Bedford, MA
Male	Global Head, Health Equity Strategy clinical trial company	Los Angeles, CA

Interviews mostly took shape organically, but some pointed questions were built in, such as:

- “What are some of the main barriers the Hispanic community faces in terms of clinical trial participation?”
- “What would you tell a family member who was hesitant about participating in a clinical trial?”
- “Who are some trusted voices in the Hispanic community?”

Interviews were conducted, recorded and transcribed over Microsoft Teams between March 11- 26, 2024.

Data Management and Analysis

Each transcript, and its corresponding recording, was reviewed thoroughly and analyzed using inductive content analysis. While examining the transcripts, important points and ideas were highlighted, and then categorized into emerging themes.

Results

The 10 interviews yielded four following interrelated themes:

Theme 1: There is a need for clear, thorough and culturally appropriate education.

Many interviewees remarked there is a lack of quality clinical trial educational materials. One person said, “...I guess the most important (issue) is really lack of understanding about what clinical trials really are...about how clinical research is run. I think that a lot of people still believe that they’re kind of Guinea pigs and so they don’t trust clinical trials. I think that mistrust is all based on just lack of knowledge about what clinical trials are.”

Misunderstanding of clinical trials may lead patients to be concerned about receiving the intervention being studied, and in turn, concerned about being placed in the control group. One person said a common question she hears is, “What if you end up getting the placebo and they just let you die?”. She goes on to say, “So that’s a common misconception in the Spanish speaking communities. Oh yeah, like half of the people in the clinical trial are gonna end up dying because they’re not even gonna get the medication.”

One participant remarked that, despite barriers, there are many Hispanic individuals open to participating in clinical trials, “So they’re open to trying something new, and they’re open to research. But then they don’t have that time to participate because they’re working full time. They have families, they have after school activities, so trying to coordinate to get them on site for screening visit, that’s gonna be... a challenge. And to ask someone to give up that many hours of their day, there’s also a challenge. Because yes, they’re interested in contributing to research. They understand that part, but they’re also interested in hopefully... hoping that maybe they’re going to benefit from being part of this clinical trial. But what are they giving up and what are they getting in return?”

Throughout the interviews, many participants spoke from the perspective of a potential participant by posing questions that might be asked, as shared below:

“What’s going to happen with this study?”

“Where is this going to be?”

“How am I going to be protected as a patient?”

“What is the trial going to do for me?”

“How are they going to keep me safe?”

“What are the risks?”

“So what are they doing with me?”

“What are they going to give me?”

“What am I going to get out of it?”

It is also imperative clinical trial education be available in Spanish when trying to reach the Hispanic population. Though this may seem obvious, availability of translated material is not ubiquitous across the clinical trial community. One participant noted, “We have had a couple of clinical trials where the sponsor...was reluctant to pay for translations of an informed consent in the beginning of the trial and wouldn’t do so until we actually had at least one or two patients speaking that specific language.” Not only does the material need to be in Spanish, but a Spanish speaker must be present when reviewing trial materials with a potential trial participant. This is to ensure that all questions are answered and to confirm the patient fully understands the informed consent before signing.

Because there are many different Spanish language dialects, it is recommended that general information aimed at raising awareness of clinical trials, be kept simple to maximize reach throughout the community.

Summary: There is a need for increased clinical trial education in the Hispanic community. General information aimed at raising awareness of clinical trials and dispelling myths should be kept simple and be available in Spanish. All clinical trial materials must also be available in Spanish, and it is imperative there is a Spanish speaking clinical research staff member available to answer questions. Patients are interested in how they will benefit from clinical trials and what they may need to give up, risks vs. benefits and how they will be cared for while in the trial.

Theme 2: Multi-stakeholder involvement improves clinical trial recruitment and retention.

While the availability of translated materials is important, it is not sufficient for empowering the Hispanic community to make informed decisions about clinical trial participation. Multiple stakeholders need to be involved to truly address the issue and support the community. Interviewees mentioned trial sponsors and staff, clinical research coordinators, care providers, family and community members as key stakeholders. Below are some remarks from interviewees about the role of different stakeholders.

Trial Sponsors and Staff

“I talk to people in these higher up positions who are not from a diverse background who are not a minority...that are making the patient recruitment decisions or the funding for the site who have no idea what you’re talking about, who have no idea all the work that goes into it and therefore do not approve funds or do not support your site to recruit diverse participants.”

“Sponsors need to commit actual resources. And I think it would have been bolstered...from an impact standpoint, significantly more if we had the sponsors understanding then what they’re starting to dial into now with regards to diversity and inclusion, which of course translates to more resource commitment. Whether that is procuring equipment or...high level study budget because you know the amount of time and effort that it took to erect those sites is not the same as if you’re going to an established site, you know that would have significantly less overhead to get these studies.”

Funders need to consider their role in alleviating the financial burdens of trial participants. One interviewee notes,

“I’m sure people are always thinking about the cost and also like...traveling somewhere else to the clinical trial and that’s another expense. But you don’t get the money in advance, so for some people it’s really hard to pay out of pocket and then wait for their reimbursement.”

Oftentimes, sponsors will turn to Hispanic community leaders for help meeting their recruitment goals. It is necessary for community leaders to be involved from the start. One participant noted, “I remember speaking with this lovely researcher, and I said to her, you know, you’ve got to reach out to me from the very beginning. I can’t fix the problem if I’m not part of solving it from the very beginning.”

Clinical Research Coordinators

“How do we bring in culturally competent clinical research coordinators that can match the composition of the people that these clinics serve?”

Care Providers

“What it boils down to is how do we inform, empower and engage the clinicians that are providing care?”

“If we want to get these patients in clinical trials, all those people that work with patients need to be on board. And so if we don’t have some of those people on board, then that’s some of the barriers, right?”

“How you are mentally supported [by providers] because there are ups and downs emotionally that go through here... because the patient’s journey is more than just a drug.”

“And also whenever you are feeling completely supported through the program, you’re more engaged and when you understand your role and how your day by day involvement in this trial makes you be a part of the end result of that gives hope to other patients afterwards, you’re also gonna be more committed.”

“But the access...it’s basically on the doctor’s point. Is he gonna think you’re gonna [participate]? You’re a good candidate for this, you know? Is he gonna refer you to this or are the social workers from the hospitals where you’re being treated? Are they actually conveying the right information? But what really makes a difference is how the hospital is included or how your doctors and social workers and hospital are actively supporting the whole process of recruitment.”

Family and Community Members

“So if you want a child to participate, you gotta get the mom to buy into this clinical trial. If you wanna get an older person, say a grandma or grandpa to participate in this clinical trial, you have to get the actual caregiver.”

“I think one of the first things, it’s not just about the recruitment, it’s about people staying in the trials. What is making you quit the trial, right? Is it your caregiver? Because if you don’t get your right support around the house or in your circle...you’re most likely to then just say this is enough, or either you’re not feeling well or you’re not seeing any difference, or you know or it is a drag to go back and forth. So that support system is important.”

“[With] immigrant men. [They have the perception that] men are big. They have this macho attitude. I’m fine. [But I say], but what about your family? What is the impact on the family? Because as you know, they are the man of the family. Are you supposed to protect them? It’s a sexist point of view, right? But that is their view of the world and I cannot change it, right?”

“We [Hispanics], ... are very family focused. You know versus individuals? We tend to be more family focused. So I think that is one of the messages about the impact on families.”

Summary: More investment and buy-in from community stakeholders, particularly those involved with the patient’s health, will improve enrollment and retention in clinical trials. Trial funders should involve community stakeholders from the beginning of trial planning to assist in meeting their recruitment goals. Care providers and research staff should feel equipped to serve the community and provide guidance through the clinical trial decision-making and enrollment process. Marketing and communication professionals should consider the role of family when preparing clinical trial materials.

Theme 3: There is mistrust of the medical system, specifically pharmaceutical companies, among the target population.

Unfortunately, the Hispanic community in the United States, like many historically underrepresented populations, has experienced mistreatment at the hands of the medical system. Many participants remarked that while physicians tend to be trusted within the Hispanic community, there is a general mistrust of the broader medical system. In particular, skepticism about pharmaceutical companies. Two participants recalled court cases in which the Hispanic community was mistreated by the medical system, including 1978’s *Madrigal v. Quilligan* where 10 Mexican American women filed a civil rights class action lawsuit against Los Angeles County-USC Medical Center for involuntary or forced sterilization.

In fact, Hispanic women have a long history of forced sterilization in the United States, with documented cases from 1907 through 2020. In 2020, more than 40 women signed an official legal petition alleging that they were medically abused by a gynecologist while in Immigration and Customs Enforcement (ICE) custody. Much like the **Black community**, the Hispanic community does not need to look very far back in their history to see examples of medical mistreatment, and in fact, many participants have experienced medical mistreatment in their own lives.

One participant discussed his experience counseling friends whose parents are considering participation in a clinical trial. He remarked, “They feel already as though their parents were not being treated the right way. I mean, they literally just haven’t been offered some of the better treatments. They just feel very dismissed by the health system. Like, you’re kind of just shuffled through and sent away and sent home. So the fact that they became aware of these clinical studies, there was half feeling like I don’t wanna do it or I don’t trust it or I don’t wanna have my parent participate.”

Another participant remarked, “It’s the day to day. It was the daily going to the hospital and being ...underpaid, mistreated. I’m giving you the example of *Madrigal v. Quilligan*, which obviously is a horrible instance, but it’s the day to day.”

It is important to note, that while the provider/patient relationship within the Hispanic community is “fragile”, as one participant phrased it, there is often a trusted bond between the two. One participant noted, “With the Latino community, they have a lot of trust in you. If you’re treating them for something, and they’ve been going to this doctor or facility for a while, they’re trusting that they have their best interests and it might not always be the case, but they’re still trusting. Whatever the doctor or PA or medical assistant tells them, they’re gonna pretty much do so. That’s why if these physicians and providers are not talking about research to them, then most likely they’re not gonna participate or it’s gonna be very hard to get them involved and research.”

Another participant said, “I feel like we [Hispanics] tend to respect physicians a lot and we tend to follow what the physician says. But also because sometimes it’s so hard for Hispanics to access the care that they don’t go to the doctor’s often. But once you go to the doctor, I feel like, yeah, they trust their physician.”

Concerns about trial participation impacting immigration status also exist. One participant remarked “One barrier is definitely immigration status. If they have to reveal whether they are legally here or not, or they don’t feel safe as far as their immigration status, then they won’t participate in a clinical trial.” Another participant remarked, “If there is not enough [in the process] that they [the patient] can trust, they’re [scared they are] gonna be sent back.”

Several participants noted mistrust of pharmaceutical companies, potentially stemming from widespread news coverage of drug prices and shortages. One participant remarked, “Like everybody understands pharmaceutical companies and they create medications, but there has been a lot of negative publicity for pharmaceutical companies and medications in the media. And then there’s been positive stuff, too. A lot of Latinos are stuck on the negative stuff. So if their doctor didn’t tell him to take this medication or recommend it, they’re very, very hesitant to try anything else.”

He goes on to say, “They also believe that pharmaceutical companies make a lot of money on these medications, and so they are hesitant if it’s something that’s not approved or prescribed to them at a pharmacy, and they’re not 100% comfortable necessarily participating in research. They don’t know if it’s gonna work.”

Another participant remarked the community believes, “Clinical trials are just like money schemes from Big Pharma but they think that the pharmaceutical companies just want to make money off them. When people see the cost of healthcare and they see the prices of their medication, it’s not that hard to believe that honestly. Yeah, like my medication. It’s like \$20,000 a month. So I don’t think any lifesaving medications should be that expensive.”

Several participants discussed how the Hispanic community get a lot of health information from Spanish-language news channels. One person said, her family “...believes everything they hear on Univision. And lately they’ve been watching a lot of YouTubers from Mexico and they also believe everything they say.” Another participant agreed that the Hispanic community places trust in their news sources and pointed out they don’t tend to get news from their health system. She said, “I know a lot of Hispanics don’t get the newsletters. They don’t even use patient portals, or they don’t subscribe to newsletters from their healthcare facilities.” This should be considered when planning communications about clinical trials.

Summary: It is important to acknowledge the history of medical mistreatment in the Hispanic community, including the news-worthy cases and the care issues that exist in today’s world. This should not preclude providers from asking patients if they want to participate in trials, but efforts discussed above (culturally appropriate materials and stakeholder involvement) should be utilized and will help address lingering mistrust, if executed well. To improve trial enrollment and retention, the trusted provider must be involved in the process from start to finish. Any “hand offs” to supporting staff, like research coordinators, must be thoughtful, so as not break the trust. Communication and marketing staff should consider the large role Spanish-language news sources (including unconventional sources like YouTube) play in attitudes and perspectives and adjust their communications accordingly.

Theme 4: Communications should discuss the impact of participation and not cease once the patient is enrolled.

Much is discussed regarding the importance of recruiting Hispanic individuals into clinical trials, but recruitment is just the start. It is short-sighted to not acknowledge the impact of participation and the logistical concerns that arise when a trial ends, both of which should be discussed during the recruitment process. Many patients are concerned that medical systems and pharmaceutical companies just want their data and that they will be forgotten about after the trial is over. Planning to discuss the “why” and the “what now?” is an important part of the education process. Below are some remarks from participants:

The Why

“[Share] the fact that these are voluntary studies and the fact that everything that is being done during a clinical trial is critical to support the science you know, so that people don’t feel like you’re unnecessarily testing random things on [them].”

One physician noted his patients don’t know what happens after the study ends and suggests this dialogue: “We’re gonna let you know the results. But we’re gonna publish them. This is where you’re gonna be able to see the results. We have specific journals, so we’re very transparent about where these are going to be, and where you can find them.”

The What Now

“The information that you get throughout the trial is important and I guess the most important part is after you are done with the trial or after you are disqualified.... Are you really disposable material or are they referring you to go back to the care that you need whenever you are not qualifying anymore or are they actually celebrating with you the time that you gave them as they published a result... which hardly ever happens.”

“I’ve also heard concerns about people thinking what’s gonna happen after the clinical trial ends. If it’s not approved, what’s gonna happen with me? And also like insurance issues like what if my insurance doesn’t approve the medication after the clinical trial?”

Summary: Data from the interviews point to a major concern within the community about being “disposed of” after the medical system or pharmaceutical company receives their data. This should be addressed during the recruitment process. It is also important to discuss the impact of the patient’s participation, how the trial will affect them in the present and future AND how their participation impacts the Hispanic community as a whole.

Conclusion

People of all backgrounds and experiences may feel hesitant about participating in clinical trials, but the stakeholder interviews completed as part of ATA provide a nuanced perspective likely held by many members of the Hispanic community. The interviews informed campaign key messages as well as communication and marketing activities.

Focus Groups

On June 10 and 13, 2024, Carly Ornstein, MPH, on behalf of the Lung Association, moderated two focus groups, in which participants discussed sample key messages. Ornstein drafted the messages based on the results from the previous research steps (literature review, landscape survey and stakeholder interviews). The objective of the focus groups was to gauge reactions to message themes and wording while procuring guidance for the ATA marketing campaign and static content.

Methods and Data Collection

Results from two separate, hour-long focus groups conducted by Ornstein, are summarized in this qualitative analysis. The focus groups generally followed the below structure:

1. Project refresher and ground rules for the focus group
2. Discussion of 11 sample messages
3. Final thoughts

All stakeholders identified as Hispanic or served the Hispanic community in a professional capacity. Stakeholders' ages ranged from 30's to 60's.

Data Management and Analysis

Each transcript, and its corresponding recording, was reviewed thoroughly and analyzed using inductive content analysis.

Results

The messages were presented in English, however final campaign messages should be available in Spanish and English. Several focus group participants expressed concern over the translation process, noting that some messages might not translate very well as written. All content should be translated from English to Spanish by a professional and then reviewed to ensure there have been no changes to the purpose, meaning and tone of the content.

Below are the messages and analysis of the feedback:

Message 1: There are many different types of clinical trials. In general, clinical trials test how a new treatment works in patients.

Response: This is a simple message, but respondents found the second sentence to be off-putting. In particular, respondents expressed concern with the word "test" because it implies the patients are being "used". One respondent noted, "Test implies subject. Subject implies not human." Respondents suggested editing the message to be more personal with suggestions like, "Clinical trials help to find better treatments for patients" or "...treatments that extend lives or offer a better quality of life". There were also suggestions to first explain what a clinical trial is and then talk about the different types of trials. Some respondents thought this would make the message flow better.

Key Takeaways: Avoid the word "test" and focus on the benefits of trials to patients.

Message 2: There are many different types of clinical trials. Clinical trials are an important part of cancer treatment. Sometimes the best treatment option for a patient is a medicine that is in development.

Response: The participants responded favorably to this message and thought it was much more personal than the previous message. Respondents also thought that the second sentence should be a key message, noting, "I think highlighting the fact that clinical trials are an important part of standard cancer treatment is important because many patients believe clinical trials are something that's completely separate from their standard therapy." There was some discussion about the accuracy of the last sentence, with one participant noting she was told a clinical trial was her only option. In general, the participants found this message to be straightforward, important and more positive than the previous message.

Key Takeaways: Messages about how clinical trials are an important part of standard cancer treatment may help patients feel at ease about participating.

Message 3: Every medicine available today was tested in a clinical trial. Just because the medicine is new, doesn't mean it is unsafe. If you participate in a clinical trial, your doctor will watch you very closely to make sure you are safe and healthy.

Response: Many participants noted they like the first sentence, "Every medicine available today was tested in a clinical trial" and use it when talking with the community, however they suggested refining it for accuracy. An example could be, "Every medicine prescribed by your doctor was once tested in a clinical trial." One participant noted, "The way I phrase it to patients ... is I explain that the drug they just received, the previous treatment was initially tested in a clinical trial and was adopted widely because it was the best treatment and this next clinical trial is geared towards finding a better treatment. And so focusing on that, the fact that clinical trials are trying to find better treatments than what we already have."

There was some negative reaction to the use of the word "unsafe" in the second sentence because it implies the trial could be risky. For the last sentence, one participant noted it would be more accurate to say, "Your research team will watch you very closely." There was additional concern over the word "healthy" since it may be misleading as a patient's overall health is never guaranteed. Some other phrasing suggestions included "Your doctor will stay by your side", "Your doctor will support you through the process to make sure that your body is responding, and your experience is a comfortable one" or "The care team is there for your wellbeing."

Key Takeaways: The words "test" and "unsafe" convey a negative tone and should be replaced. Also, using "when you participate" instead of "if you participate" makes the language more empowering. This message is important but needs a few wording changes for improved accuracy and empathy. A suggested variation based on feedback would be, "Every medicine you've been prescribed from your doctor was once approved after being in a clinical trial. New medicines can offer patients many benefits. When you participate in a trial, your care team will support you through the entire process."

Message 4: Clinical trials are highly monitored research studies. They test how well a new medicine works. Patients receive the highest level of care possible in clinical trials and can leave the trial at any time.

Reaction: There were dividing opinions on this message. For the first sentence, some participants found it reassuring and others found it too clinical. One participant suggested combining everything into one message: "Patients receive the highest level of care possible in clinical trials and can leave the trial at any time." Some participants felt it was important to state that trial participants can leave at any time citing it helps patients feel more control over their situation and is a guiding principle in informed consent. Others felt the phrasing is not as empowering and suggested focusing more on why participation is important. One participant said, "I think really stressing that the patients who participate, that their feedback is important to the trial—is really critical here."

Key Takeaways: This message needs more intentional preparation to strike the right balance. Due to the divisiveness of the message, the gestalt of the message may be more suitable for static web content instead of a social media post.

Message 5: Clinical trials are an important part of medicine. They help doctors learn more about medicines that could improve someone's life. They also provide patients with medicines they might not be able to get outside of a trial.

Reaction: Participants agreed the first sentence is important, but some felt it was too vague. This sentence

would resonate better if there were examples of how clinical trials have been important in medicine and how someone's participation makes a difference. One participant said, "You will get a lot more engagement rather than just saying that it's important for medicine...saying why it is important". One participant suggested adjusting it slightly to read, "Clinical trials are a normal or important (either way), standard part of cancer treatment."

In the second sentence, participants reacted positively to the sentiment of improving someone's life and found it to be a good description of clinical trials. They also reacted positively to the last sentence, but suggested making it more accurate by saying "medicines and treatment protocol" or something that alludes to the full care a patient will receive, not just the drug.

Key Takeaways: As discussed, positive sentiments with clear benefits test well. Anything that implies history, like the first sentence, would benefit from a communication modality in which there can be a more detailed and nuanced discussion of the topic. This message might be best delivered through videos and personal stories. There are benefits to normalizing clinical trials and their role in healthcare. When possible, messages should not only focus on the medication, but about the whole clinical trial experience.

Message 6: If you participate in a clinical trial, you are not a lab rat or Guinea pig. There are many protections in place to keep patients safe at all times.

Response: Respondents agreed they often hear this exact concern from Hispanic patients, and it is important to address it. Both focus groups agreed it could be very valuable in a "Myth vs. Reality" style message. Alone, the message is too harsh and off-putting. But in the right context, perhaps in a quippy social media post using the myth-busting format, the message could be very powerful.

There was some discussion about the last sentence. Some participants liked it, and others were exploring variations like "participant's rights, and safety are assured."

Key Takeaways: This is an important message, but the delivery is more important. As discussed, a myth-busting social media post could be an appropriate delivery mechanism. There are many ways to dispel the myth, but the sentiments should be empowering, and the language should be chosen carefully, as words that are too clinical might reinforce the feeling of being a test subject.

Message 7: Right now, most people who participate in clinical trials are white, which means many Hispanic Americans are not accessing important medications. It also means, researchers aren't able to learn enough about how certain medicines work for Hispanic people.

Reaction: Participants preferred rephrasing the first sentence to be less oppositional and instead say "Historically, Hispanic Americans have been heavily underrepresented in the clinical trial process." Participants largely agreed this is an important message but needs more context to be effective. One participant noted, "We are built differently. Our genes adapt to medicine differently. So I guess that's the most important part of having a comprehensive study. It's not because we're black, brown or white. It's because of how we are, how we are throughout, you know, through our genes." Calling attention to the disparity seemed important to the participants, because it can inspire change. One participant noted, "I think it'll be beneficial [to talk about this] because when people realize that they have the power to change things, it makes a difference, even if it's not just for them, but for others within their community."

Key Takeaways: Campaign messaging should include discussion of the disparity, but in a way that is empowering versus aggressive. For a nuanced discussion, this type of message might be best suited for a blog post or static content. However, there may be an opportunity for social media posts using graphics to visually show the disparity and focus on how participation can help an individual and their community.

Message 8: 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.

Reaction: This message was well-received by the participants. One person said, “I think this one works and if we translate it into Spanish, I think it will resonate with the Hispanics a lot because one of the main things for our community is to have more time with our loved ones.” Another noted, “That’s what they want. They want an extension of their life because they want to be there for their family. Especially in Latino communities, you know, you’re raised from the minute you’re born: family first.”

Key Takeaways: This is a very powerful message that should be used in the campaign. Culturally appropriate images should accompany this message. As is, the message tested very well. If altered, it should be sure to retain qualifying words like “might” and “could” as to not be misleading.

Message 9: When you participate in a clinical trial, not only are you accessing high-quality cancer care, you are contributing to cancer research which might save someone’s life in the future.

Reaction: This message tested well. To become even more personal and impactful, one participant suggested changing it to say “...which might save your life or your loved one’s life in the future” or “...could impact the lives of your children and grandchildren or future generations.” Several participants noted that in their work with Hispanic patients, the patient’s desire to help others often comes up in conversation, so this is likely an effective message.

Key Takeaways: This message is strong in that it explains the benefits of a trial for the patient as well as the patient’s family and community—which are two strong parts of many Hispanic cultures.

Message 10: The Hispanic patient experience matters in research. When more Hispanic people are represented in clinical trials, researchers can learn more about the best medicines to treat Hispanic patients.

Reaction: This message read as too vague for many participants. The concepts require more explanation to be trusted by the target audience. One participant noted it could be perceived as “fake news” because there is no evidence or data in the message. The first sentence reads as too commercial and impersonal but could be more engaging just by changing it to say, “Your experience matters...” (instead of “The Hispanic patient experience...”).

Key Takeaways: This is an important topic to cover but feels impersonal as written. It could probably be grouped in with Message 7 in a way that conveys why it matters that Hispanic individuals participate in clinical trials, but with a warm, personal and trusting tone.

Message 11: When you are discussing treatment options with your doctor, let them know you are interested in learning more about clinical trials.

Reaction: This message could be more specific and more empowering. One participant recommended changing it to “When you see your doctor, ask them if there is a clinical trial that’s right for you.” Participants agreed this call to action needs to come after educational messages.

Key Takeaways: This call to action should have patients asking their providers if there is a clinical trial right for them or if they are eligible for a clinical trial. Ideally there will be a conversation guide for patients within the content. The call to action should always come after the explanatory messages.

In addition to discussing the messages, the participants shared thoughts on images and copy:

Images: Several participants mentioned the important role of images in communication campaigns. Campaign images that feature people should resonate with a Hispanic audience and consider the heterogeneity of the Hispanic population. One participant noted, “I’ve always said that we have quite a few flavors...You have someone who looks African American. You have someone who can look Chinese. You can have someone who looks very Caucasian and then what many people consider the Latino, which is, you know, dark skin with dark hair.” It is important the images are recognizable to the population but also show a variety of Hispanic people.

Copy: Much thought should go into how and when English versus Spanish copy is used. Some participants suggested having both languages in one post but making it a carousel style. Others suggested having English and Spanish social media messages published on different days, as to not crowd the post. Communication staff should research best practices, noting that all communications must be available and easily accessible in Spanish.

Conclusion

As health educators and trial staff prepare messaging about clinical trials for the Hispanic community, they should carefully consider the wording and phrasing of the copy in both Spanish and English. A message may lose its efficacy if it comes across as too clinical, formal, combative or forthright. Clear messages with a hopeful and empowering tone may perform better with the target audience. Often altering one word or phrase can change the tone of the entire message, which is one reason why expert translation is necessary for this project.

The two messages best received by the focus groups were:

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.

When you participate in a clinical trial, not only are you accessing high-quality cancer care, you are contributing to cancer research which might save someone’s life in the future.

Below are additional best practices that emerged from the focus groups:

- Use “when” language instead of “if”. (e.g.: “When you participate in a clinical trial...”)
- Giving clinical trials context may help reduce fear. (e.g.: “Every medicine you’ve been prescribed from your doctor was once approved after being in a clinical trial. New medicines can offer patients many benefits.”)

- When possible, messages about the benefits of clinical trials should not only focus on the medication, but about the whole clinical trial experience.
- Using a “myth-busting” messaging set-up may help to connect with the audience by using their own words without triggering the reader.
- Clinical words like “watched”, “monitored”, “test” and “subjects” may play into the audience’s fears. It is important to discuss clinical trial safety precautions using supportive and empowering words. (e.g. “When you participate in a trial, your care team will support you through the entire process.”)
- Campaign images of people should be diverse representations of Hispanics.
- Graphics may help explain the disparity in terms of numbers, which may provide more credibility to the message.
- Never overpromise in messaging. Use qualifiers like “might”, “may” and “could” to sound hopeful, yet realistic.
- Respondents suggested a call to action that involves asking rather than telling. (e.g.: “When you see your doctor, ask them if there is a clinical trial that’s right for you.”)

All focus group participants offered to review any draft messaging and assist in ensuring the translations retain the intent of the message. The participants were also grateful and excited for this campaign and remarked that when organizations or companies seek community input, it shows they are taking the issue seriously and committed to serving the target audience. With careful consideration of the points discussed in this document, as well as the results from the stakeholder interviews and landscape survey, the Lung Association crafted multiple assets and a corresponding marketing campaign informed by the target audience.

Final Educational Assets

The Lung Association developed four videos featuring two stakeholders with personal clinical trial experience, as well as an informative website, available in English and Spanish.

Video 1 - [Irisaida’s Story on Lung Cancer and Clinical Trials \(English\)](#)

Video 2 - [Irisaida’s Story on Lung Cancer and Clinical Trials \(Spanish\)](#)

Video 3 - [Ivis Febus-Sampayo on Awareness for Clinical Trials \(English~30s, with Spanish subtitles\)](#)

Video 4 - [Ivis Febus-Sampayo on Awareness for Clinical Trials \(English~90s, with Spanish subtitles\)](#)

Website: [English](#) | [Spanish](#)

Campaign Feedback Survey

The Research & Evaluation Group at Public Health Management Corporation (PHMC) conducted a campaign feedback survey with 449 total responses, from individuals 18+ who identify as Hispanic/Latino/a/x (may also identify as another race or ethnicity) and reside in one of the four determined metro areas: Port St. Lucie, FL (2%), Fort Lauderdale/Miami (58.4%), FL, Albuquerque/Santa Fe, NM (14%) and Las Vegas, NV (25.6%). Respondents were randomly branched into three options to see two assets:

1. Video 2 and Website: 33%
2. Video 3 and Website: 33%
3. Video 1 and Video 4: 34%

Legend:

Video 1 - [Irisaida's Story on Lung Cancer and Clinical Trials \(English\)](#)

Video 2 - [Irisaida's Story on Lung Cancer and Clinical Trials \(Spanish\)](#)

Video 3 - [Ivis Febus-Sampayo on Awareness for Clinical Trials \(English ~30s, with Spanish subtitles\)](#)

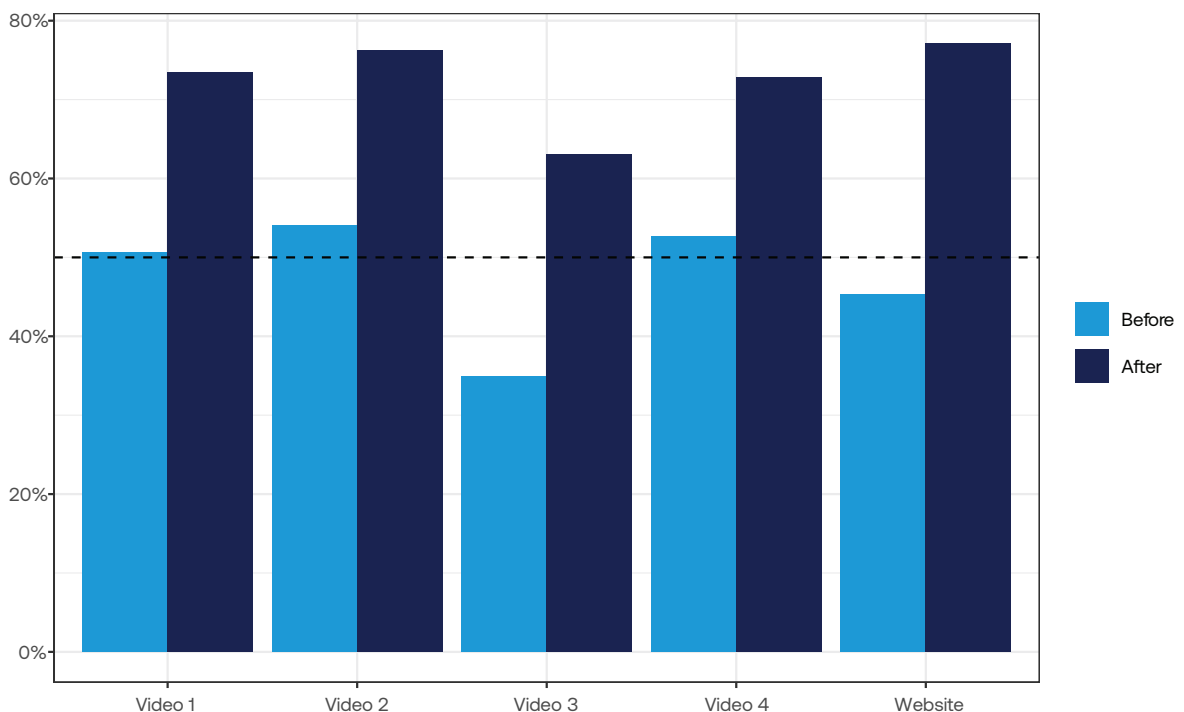
Video 4 - [Ivis Febus-Sampayo on Awareness for Clinical Trials \(English ~90s, with Spanish subtitles\)](#)

Website: [English](#) | [Spanish](#)

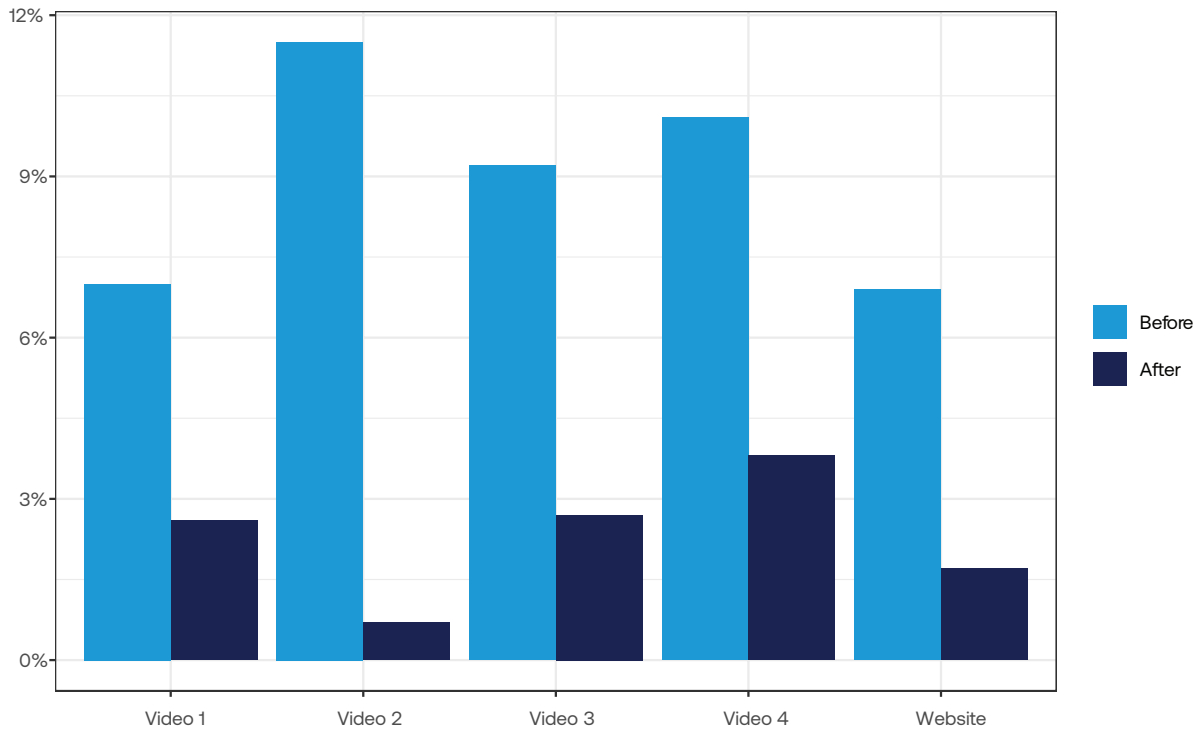
Campaign Viewed	Views (Randomized)
Video 1	158
Video 2	139
Video 3	152
Video 4	158
Website	291
Total	898

All respondents, regardless of which assets they viewed, reported an increase in positive attitudes (Chart F) and decrease in negative attitudes (Chart G) toward clinical trials after viewing the assets.

Percent of respondents with a positive attitude towards clinical trials. (Chart F)

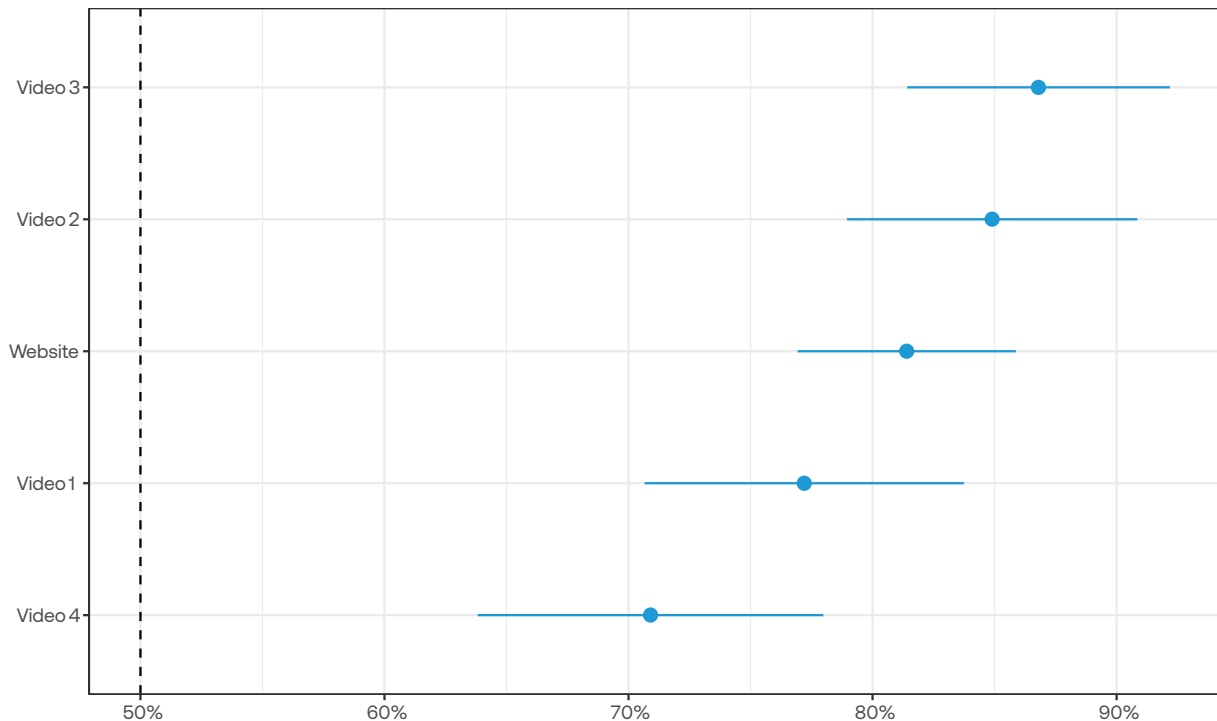


Percent of respondents with a negative attitude towards clinical trials. (Chart G)

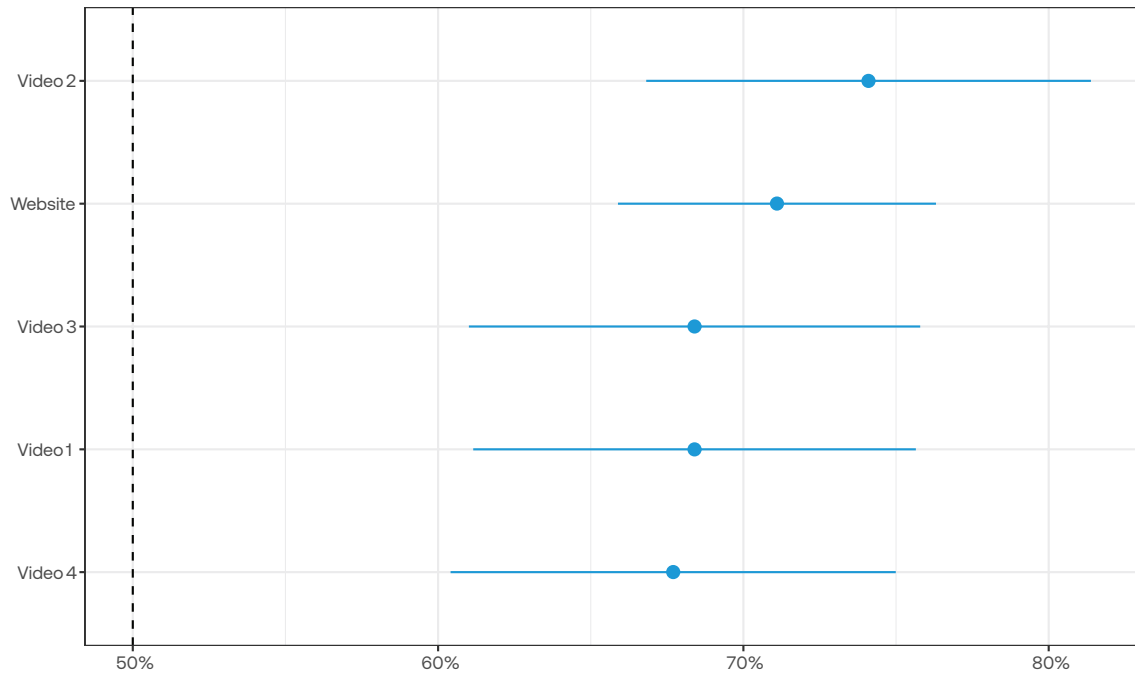


Additionally, regardless of asset viewed, the majority of participants indicated they learned something new (Chart H), are more likely to consider a clinical trial (Chart I), thought the campaign clearly communicated the importance of clinical trials (Chart J) and were likely or very likely to share the campaign with others (Chart K).

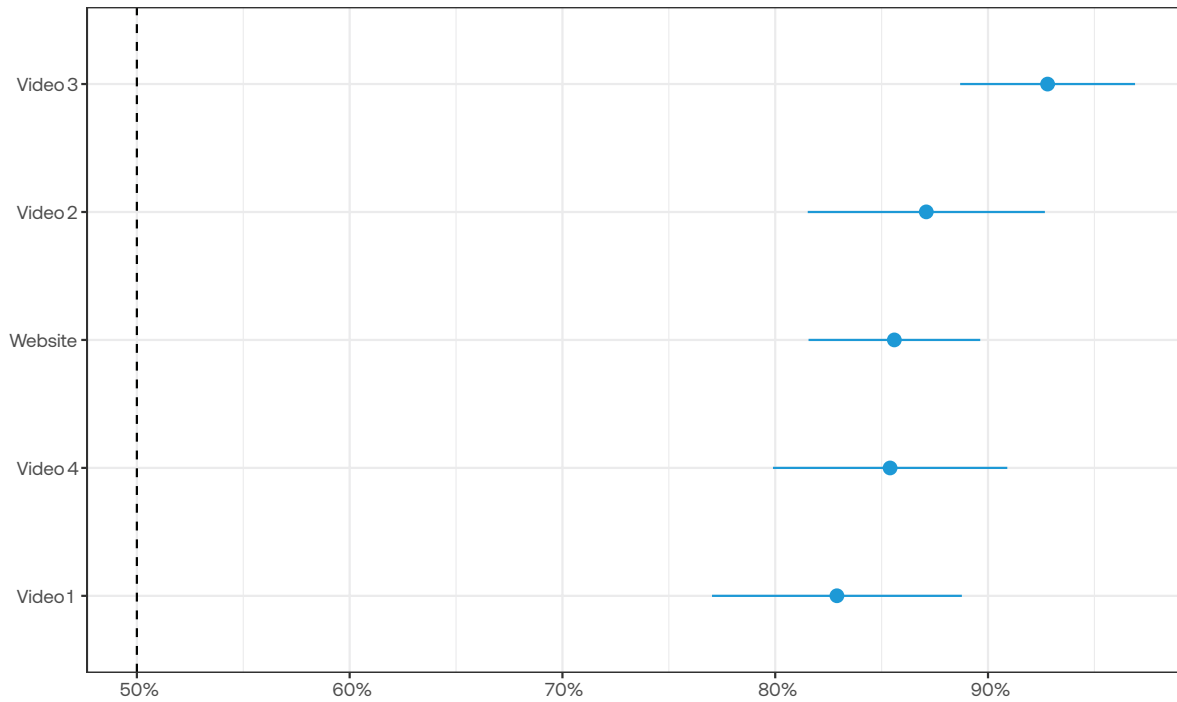
“I learned something new after viewing the campaign.” (Chart H)



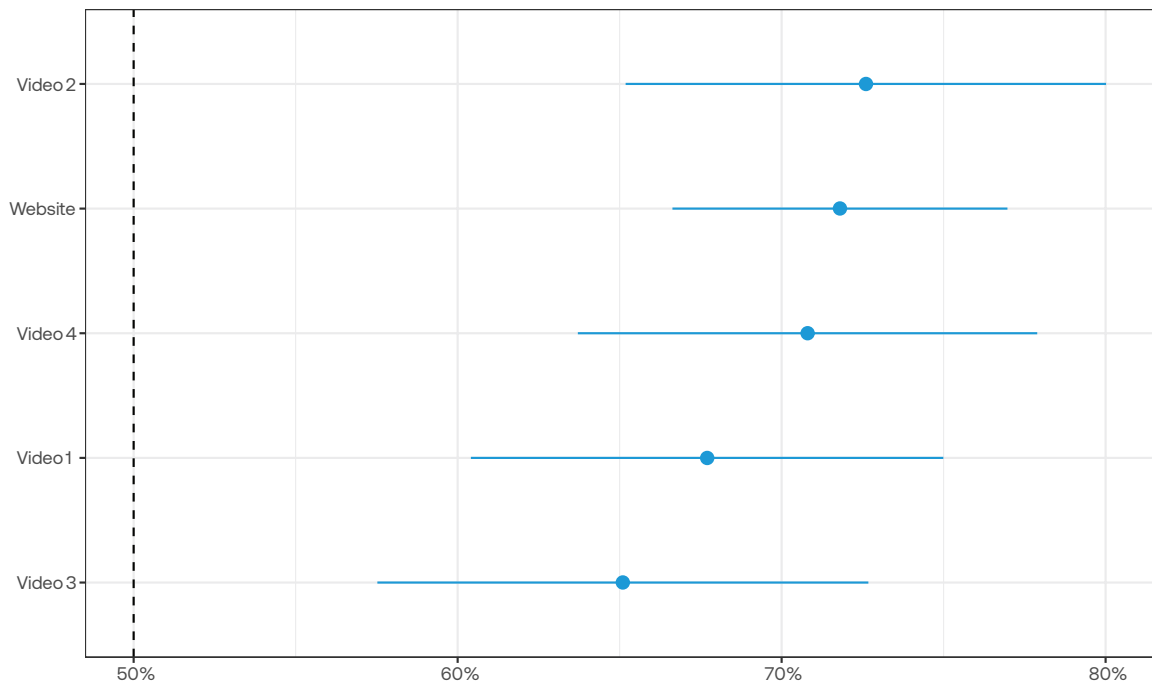
“I am more likely to consider a clinical trial.” (Chart I)



“The campaign clearly communicated the importance of clinical trials.” (Chart J)



I am likely/very likely to share the campaign message with others? (Chart K)



Though all assets performed well, videos two ([Irisaida’s Story on Lung Cancer and Clinical Trials- Spanish](#)) and three ([Ivis Febus-Sampayo on Awareness for Clinical Trials-English ~ 30s, with Spanish subtitles](#)) were consistently well-received by respondents.

The data show that all assets produced improved thoughts and attitudes toward clinical trials and that the project benefits from the variety of resources available. Members of the target audience may share commonalities due to their shared heritage, but it is important to remember that shared background does not equate homogeneity among the target population. Assets delivered by different people, in various formats and languages help the campaign resonate more with the target audience.

Conclusion

The data collected through this ATA project paints a complex picture of a diverse community where conflicting attitudes of medical mistrust but the desire to be included are in the foreground. Concerns about participating in clinical research are often likely abated through thoughtful communication. When information is presented in an accessible or relatable way, individuals are poised to make informed decisions. Much of the Hispanic community does not receive the resources needed to make informed decisions. Or, because there are no practices in place to address language and access barriers, the decision to decline participation in clinical research may be made for them. Public health campaigns like ATA help provide much needed context about clinical trials to the public. Context sets the stage for medical professionals and research staff to engage potential participants in communication about trials, but coordinated follow-through with patients as they proceed through a trial solidifies trust and is important in changing long-term attitudes toward clinical research. Architects of future educational campaigns are urged to draw on the findings discussed in this document and involve the community in the planning and dissemination of campaigns.

Acknowledgments

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This document was prepared by Carly Ornstein, MPH and reviewed and designed by the American Lung Association.

Appendix

Literature Review

As prepared by Public Health Management Corporation (PHMC)

Aragones, Abraham, et al. “Characterization of the Hispanic or Latino Population in Health Research: A Systematic Review.” *Journal of Immigrant and Minority Health / Center for Minority Public Health*, vol. 16, no. 3, 2014, p. 429, <https://doi.org/10.1007/s10903-013-9773-0>. Accessed 3 Apr. 2024.

The lack of detailed characterization of the Hispanic research subjects can ultimately create roadblocks in translating evidence into practice when providing care to the large and increasingly diverse Hispanic population in the US. This review highlights the need to account for multiple variables, including at least race, ethnicity, country of origin, language, years in the US, and socioeconomic status to provide accurate interpretation of health indicators and helpful information in translational research. However, this is not current practice. While accurate interpretation of health indicators is certainly fundamental to translating evidence into practice, to improve the adaptation, dissemination, and adoption of evidence-based interventions, health researchers must change their data collection methodology to include at a minimum the variables described above. The adoption of a new set of characterization standards beyond ethnicity will serve as an important foundational step to overcoming the many health disparities existing in the Hispanic population in the United States.

Luis E. Raez et al., Challenges in Genetic Testing and Treatment Outcomes Among Hispanics With Lung Cancer. *JCO Oncol Pract* 18, 374–377(2022). DOI:10.1200/OP.22.00096

Lung cancer is a public health problem and causes more deaths than any other cancer. 1-3 We expect to have 130,000 deaths in the United States in 2021, and more than 60,000 deaths per year have been registered in Latin America (LATAM).4,5 Hispanics are the largest minority group in the United States (18% of the population), and there are more than 20 countries with Hispanic populations in LATAM. Disparities in the diagnosis and clinical outcomes of Hispanic patients with lung cancer compared with non-Hispanic White (NHW) patients are well documented. Hispanics have disadvantages in social determinants of health: access to care, health insurance, cultural differences, and immigration status. Moreover, there are also genetic and other biological differences that need to be considered. Hispanics in LATAM have some extra hardships; most of them live in countries classified as low- and middle-income countries. In this editorial, we comment on disparities in genetics, biomarker testing, and therapy outcomes in Hispanic patients with lung cancer in the United States and abroad, which significantly affect access to precision medicine and survival.

Samuel, Cleo A., et al. “Calidad de Vida: A Systematic Review of Quality of Life in Latino Cancer Survivors in the USA.” *Quality of Life Research*, vol. 29, no. 10, 2020, pp. 2615–30. JSTOR, <https://www.jstor.org/stable/48734013>. Accessed 4 Apr. 2024.

Of the 648 articles reviewed, 176 met inclusion criteria, with 100 of these studies focusing exclusively on breast cancer patients and no studies examining end-of-life HRQOL issues. Compared with other racial/ethnic groups, Hispanics/Latinos reported lower HRQOL and a higher symptom burden across multiple HRQOL domains. Over 80% of studies examining racial/ethnic differences in psychological well-being (n = 45) reported worse outcomes among Hispanics/Latinos compared with other racial/ethnic groups. Hispanic/Latino cancer survivors were also more likely to report suboptimal physical well-being in 60% of studies assessing racial/ethnic differences (n = 27), and Hispanics/Latinos also reported lower social well-being relative to non-Hispanics/Latinos in 78% of studies reporting these outcomes (n = 32). In contrast, reports of spiritual well-being and spirituality-based coping were higher among Hispanics/Latinos cancer survivors in 50% of studies examining racial/ethnic differences (n = 15).

Lindberg, Nangel M et al. “Creating accessible Spanish language materials for Clinical Sequencing Evidence-Generating Research consortium genomic projects: challenges and lessons learned.” *Personalized medicine* vol. 18,5 (2021): 441-454. doi:10.2217/pme-2020-0075

Aim: To increase Spanish speakers’ representation in genomics research, accessible study materials on genetic topics must be made available in Spanish. **Materials & methods:** The Clinical Sequencing Evidence-Generating Research consortium is evaluating genome sequencing for underserved populations. All sites needed Spanish translation of recruitment materials, surveys and return of results. **Results:** We describe our process for translating site-specific materials, as well as shared measures across sites, to inform future efforts to engage Spanish speakers in research. **Conclusion:** In translating and adapting study materials for roughly 1000 Spanish speakers across the USA, and harmonizing translated measures across diverse sites, we overcame numerous challenges. Translation should be performed by professionals. Studies must allocate sufficient time, effort and budget to translate and adapt participant materials.

Palmer, Nynikka R et al. “Prostate cancer patients’ self-reported participation in research: an examination of racial/ethnic disparities.” *Cancer causes & control : CCC* vol. 32,10 (2021): 1161-1172. doi:10.1007/s10552-021-01463-9

Purpose: We examined prostate cancer patients’ participation in research and associated factors by race/ethnicity in a multiethnic sample. **Methods:** Men with a new diagnosis of prostate cancer were identified through the California Cancer Registry. Patients completed a cross sectional telephone interview in English, Spanish, Cantonese or Mandarin. Multivariable logistic regression models, stratified by race/ethnicity, estimated the associations of patient demographic and health characteristics with participation in (1) any research, (2) behavioral research, and (3) biological/clinical research. **Results:** We included 855 prostate cancer patients: African American (19%), Asian American (15%), Latino (24%), and White (42%). In the overall model of participation in any research, African American men (Odds Ratio (OR) = 2.54, 95% CI 1.63-3.94), and those with two or more comorbidities (OR = 2.20, 95% CI 1.27-3.80) were more likely to report participation. Men 65 years old and older (OR = 0.65, 95% CI 0.47-0.91), those who were married or living with a partner (OR = 0.67, 95% CI 0.45-0.98), and those who completed the interview in Spanish (OR = 0.36, 95% CI 0.15-0.85) were less likely to report participating in any research. Stratified analyses identified racial/ethnic-specific sociodemographic characteristics associated with lower research participation, including Spanish or Chinese language, older age, and lower education. **Conclusion:** African American prostate cancer patients reported higher research participation than all other groups. However, recruitment efforts are still needed to overcome barriers to participation for Spanish and Chinese speakers, and barriers among older adults and those with lower education levels.

Kaplan, Celia P et al. “Knowledge and attitudes regarding clinical trials and willingness to participate among prostate cancer patients.” *Contemporary clinical trials* vol. 45,Pt B (2015): 443-448. doi:10.1016/j.cct.2015.09.023

Background: Enrollment of minorities in clinical trials remains low. Through a California population-based study of men with early stage prostate cancer, we examined the relationships between race/ethnicity and 1) attitudes, 2) knowledge and 3) willingness to participate in clinical trials. **Methods:** From November 2011-November 2012, we identified all incident cases of prostate cancer in African American, Latino, and Asian American men ages 18-75 years, and a random sample of white men diagnosed in 2008, through the California Cancer Registry, living within 60 miles of a site offering ≥ 1 clinical trial. Participants completed a 30-min telephone interview in English, Spanish, or Chinese. In this cross-sectional population-based study, multivariable logistic regression was used to estimate associations between race/ethnicity and 1) attitudes, 2) knowledge and 3) willingness to participate. **Results:** Of 855 participants, 52% were ≥ 65 years, 42% were white, 24% Latino, 19% African American and 15% Asian American. The majority (81%) had medium-to-high health literacy. Compared to non-Latino white men, African American men were less likely to

have above average knowledge of clinical trials (OR=0.55; CI=0.35-0.86), as were Asian American (OR=0.55; CI=0.33-0.93) and Latino men (OR=0.30; CI=0.18-0.48). There were no racial/ethnic differences in willingness to participate. The attitude that “researchers are the main beneficiaries” was negatively associated with willingness (OR=0.63; CI=0.43-0.93); the attitude that “patients are the main beneficiaries” was positively associated with willingness to participate (OR=1.57; CI=1.07-2.29). **Conclusions:** Men with early stage prostate cancer are willing to take part in clinical trials and this willingness does not vary by race/ethnicity.

Echeverri, Margarita et al. “Cancer Health Literacy Test-30-Spanish (CHLT-30-DKspa), a New Spanish Language Version of the Cancer Health Literacy Test (CHLT-30) for Spanish-Speaking Latinos.” Journal of health communication vol. 21 Suppl 1,Suppl (2016): 69-78. doi:10.1080/10810730.2015.1131777

This article describes the adaptation and initial validation of the Cancer Health Literacy Test (CHLT) for Spanish speakers. A cross-sectional field test of the Spanish version of the CHLT (CHLT 30-DKspa) was conducted among healthy Latinos in Louisiana. Diagonally weighted least squares was used to confirm the factor structure. Item response analysis using 2-parameter logistic estimates was used to identify questions that may require modification to avoid bias. Cronbach’s alpha coefficients estimated scale internal consistency reliability. Analysis of variance was used to test for significant differences in CHLT-30-DKspa scores by gender, origin, age and education. The mean CHLT-30-DKspa score (N = 400) was 17.13 (range = 0-30, SD = 6.65). Results confirmed a unidimensional structure, $\chi^2(2)(405) = 461.55$, $p = .027$, comparative fit index = .993, Tucker Lewis index = .992, root mean square error of approximation = .0180. Cronbach’s alpha was .88. Items Q1-High Calorie and Q15-Tumor Spread had the lowest item-scale correlations (.148 and .288, respectively) and standardized factor loadings (.152 and .302, respectively). Items Q19- Smoking Risk, Q8-Palliative Care, and Q1-High Calorie had the highest item difficulty parameters (difficulty = 1.12, 1.21, and 2.40, respectively). Results generally support the applicability of the CHLT-30-DKspa for healthy Spanish-speaking populations, with the exception of 4 items that need to be deleted or revised and further studied: Q1, Q8, Q15, and Q19.

Gonzalez, Sara et al. “Consent for Use of Genetic Data among US Hispanics/Latinos: Results from the Hispanic Community Health Study/ Study of Latinos.” Ethnicity & disease vol. 31,4 547-558. 21 Oct. 2021, doi:10.18865/ed.31.4.547

Inclusion of historically underrepresented populations in biomedical research is critical for large precision medicine research initiatives. Among 13,721 Hispanic Community Health Study/Study of Latinos (HCHS/SOL) enrollees, we used multivariable-adjusted prevalence ratios to describe characteristics associated with participants’ willingness to consent to different levels of biospecimen and genetic data analysis and sharing. At baseline (2008-2011), HCHS/SOL participants almost universally consented to the use of biospecimens and genetic data by study investigators and their collaborators (97.6%; 95%CI: 97.1, 98.0). Fewer consented to biospecimen and genetic data sharing with investigators not affiliated with the HCHS/SOL research team (81%, 95%CI: 80, 82) or any data sharing with commercial/for-profit entities (75%, 95%CI: 74, 76). Those refusing to share their data beyond the study investigators group were more often females, Spanish language-speakers and non-US born individuals. As expected, participants who were retained and re-consented at the six-year follow up visit tended to embrace broader data sharing, although this varied by group. Over time, Puerto Ricans and Dominicans were more likely to convert to broader data sharing than individuals of a Mexican background. Our analysis suggests that acculturation and immigration status of specific Hispanic/Latino communities may influence decisions about participation in genomic research projects and biobanks.

Rodríguez, Vivian M et al. “A Qualitative Exploration of Latinos’ Perceptions About Skin Cancer: the Role of Gender and Linguistic Acculturation.” Journal of cancer education : the official journal of the American Association for Cancer Education vol. 32,3 (2017): 438-446. doi:10.1007/s13187-015-0963-4

Latinos have the highest rate of skin cancers among U.S. minorities. Despite a rising incidence of melanoma—the deadliest form of skin cancer—and greater disease burden, Latinos tend to have poor awareness of skin cancer risk factors which may inhibit preventive action. We expanded on prior work by qualitatively examining potential moderators (i.e., gender, acculturation) of skin cancer perceptions among Latinos from El Barrio in Harlem, New York City. Four focus groups stratified by language (English/Spanish) and gender were conducted. Discussions were recorded, transcribed, and coded using thematic analysis. Thirty-eight self-identified Latinos (32 % male) participated. Across groups, median age was 35 years; 50 % completed <high school degree, 82 % had annual incomes ≤\$29,999, and 55 % were born in Mexico. Mean acculturation level was 8.5 (SD = 3.9, range = 4-20). Major themes included (1) knowledge of common skin cancer risk factors, (2) acknowledgment of personal risk although lighter-skin individuals are at greater risk, and (3) awareness of effective risk reduction methods, despite the presence of fatalistic beliefs. Compared to males, females discussed tanning norms and appearance-based factors, identified children as vulnerable, highlighted the benefits of sun exposure, and wanted more information. Few linguistic acculturation patterns were noted; English speakers questioned the carcinogenic effect of sunscreen and reported more skin cancer-related physician discussions than Spanish speakers. Despite generally low acculturation, Latinos correctly identified skin cancer risk factors and agreed that it is preventable with engagement in risk-reducing behaviors. Future educational interventions must capitalize upon and reinforce such beliefs and address fatalistic perceptions which may hinder prevention efforts.

Lola A. Fashoyin-Aje et al., Enrollment of Hispanics in cancer clinical trials: An FDA analysis. JCO 36, e18670-e18670(2018). DOI:10.1200/JCO.2018.36.15_suppl.e18670

Background: New Drug- and Biologics License Applications are required to include demographic data, including data on race/ethnicity, according to categories set forth in the Office of Management & Budget (OMB) Directive 15, which defines 5 race categories: American Indian/Alaska Native, Asian, Black/ African American, Native Hawaiian/ Other Pacific Islander, or White, and 2 ethnicity categories (Hispanic/Latino or Not Hispanic/Latino). The Directive was intended to identify potential lack of representation of demographic subgroups to enable redress early in CT conduct. We assessed the proportion of patients identified as ‘Hispanic/Latino’ (Hispanic) in clinical trials (CTs) supporting the approval of new drugs for the treatment of solid tumor malignancies. Methods: We reviewed the marketing applications of approved new cancer drugs between 2011- 17, to identify CTs that provided the primary safety and efficacy data. Demographic data were pooled across trials and analyzed in aggregate. Results: Hispanic patients represented 2.5% (n = 906) of the total population; 35% were enrolled in the US and 77% reported ‘White’ race. The majority of Hispanic patients enrolled outside the US were enrolled in sites in Spain (23%), Brazil (18%), Italy (11%) and France and Mexico (7% each). Patients who reported Hispanic ‘race’ represented 0.21% of all patients. Conclusions: Census estimates indicate that Hispanics comprise 11% of the US population. This analysis suggests that patients who report Hispanic ‘ethnicity’ or ‘race’, may be underrepresented in CTs. This finding is limited by inconsistencies in the reporting of race/ethnicity data in the applications we reviewed. For many patients, ‘ethnicity’ was not collected or, reporting did not meet FDA requirements. Measures are needed to ensure that the data submitted to the FDA meet the requirements of OMB Directive 15. Most patients reporting ‘Hispanic’ ethnicity were enrolled in European sites. This subgroup may not be representative of the Hispanic population in the US which predominantly reflects emigration from Mexico and Central America.



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