# ADVANCING THE SCIENCE OF CANCER IN LATINOS

## 2024 Conference Proceedings

ADVANCING
THE SCIENCE OF CANCER
IN LATINOS

UT Health
San Antonio
Institute for Health
Promotion Research

UT Health
San Antonio
Mays Cancer Center

2025

# ABOUT

## Advancing the Science of Cancer in Latinos: 2024 Conference Proceedings

Dr. Amelie G. Ramirez of the *Salud America!* program and the Institute for Health Promotion Research at UT Health San Antonio partnered with the Mays Cancer Center at UT Health San Antonio to create the *Advancing the Science of Cancer in Latinos* biennial conference.

The 2024 event on Feb. 21-23, 2024, in San Antonio, Texas, welcomed over 280 prominent researchers, physicians, healthcare professionals, patient advocates, and students from across the globe to address cancer among Latinos and all people.

Conference sponsors included: platinum supporters Amgen, AstraZeneca, Bristol Myers Squibb, Genentech, and Gilead; silver supporters GMaP Region 3, Loxo@Lilly, National Cancer Institute, Pfizer, and Regeneron; and cancer center supporters Arizona Comprehensive Cancer Center, Sylvester Comprehensive Cancer Center, UCSD Moores Cancer Center in partnership with UCSD Center for Health Equity Education, and VCU Massey Comprehensive Cancer Center.

Scientific planning committee members included: Chair, Amelie G. Ramirez, DrPH, UT Health San Antonio; Co-chair, Edward J. Trapido, ScD, FACE, Louisiana State University; Barbara Segarra-Vázquez, DHSc, MT, University of Puerto Rico; Alejandro Recio Boiles, MD, FACP, University of Arizona; Maria Constanza Camargo, National Cancer Institute; Filipa C. Lynce, MD, Harvard University; Gerardo Colon-Otero, MD, Mayo Clinic, Florida; Katherine Y. Tossas, PhD, Virginia Commonwealth University; Laura Fejerman, PhD, MSc, University of California, San Francisco; Mariana C. Stern, PhD, University of Southern California; Martin Mendoza, PhD, Centers for Medicare and Medicaid Services and Office of Minority Health; Matthew P. Banegas, PhD, MPH, University of California, San Diego; Patricia I. Moreno, PhD, Miami University; and Sandi Stanford, Alamo Breast Cancer Foundation.

The following “Advancing the Science of Cancer in Latinos: 2024 Conference Proceedings” summarizes presentations and panels. Discussion covered new research advances on clinical best practices, effective community interventions, system-change advocacy, and professional training to reduce cancer in Latinos and all people.

## CONFERENCE SPONSORS

### Platinum Sponsors

AMGEN

AstraZeneca

Bristol Myers Squibb™

Genentech
A Member of the Roche Group

GILEAD
Creating Possible

### Silver Sponsors

NE CO KS AZ NM OK TX
GMaP
Region 3

NIH NATIONAL CANCER INSTITUTE

Pfizer

REGENERON

LOXO@Lilly

## Cancer Center Supporters

Center for Health Equity Education Research

UC San Diego
MOORES CANCER CENTER

THE UNIVERSITY OF ARIZONA
Cancer Center

MASSEY
CANCER CENTER
VCU

SYLVESTER
COMPREHENSIVE CANCER CENTER
UNIVERSITY OF MIAMI HEALTH SYSTEM

## Exhibitors

agios

AstraZeneca

blueprint™
MEDICINES

CARIS®
LIFE SCIENCES

EXACT SCIENCES

IMMUNOCORE

Jazz Pharmaceuticals.

MERCK

All of Us
RESEARCH PROGRAM
National Alliance for Hispanic Health®

Pfizer

## TABLE OF CONTENTS

# INTRODUCTION

## Healthcare Inequity in the Latinx Community

The Latinx population both within and outside the US has significant heterogeneity. [Velazquez-Villarreal] After all, Latin America has been a melting pot of mixed populations for 500 years, with over 20 heritage groups recognized by the Hispanic Community Health Study/Study of Latinos. These groups are distinct, with unique culture, language, and US influence, but are also connected by more similarities than differences. [Perez-Stable]

Latinx individuals are the largest and youngest minority in the US and are projected to account for more than half of the overall growth through 2060. Compared to non-Hispanic White individuals, Latinx individuals are more likely to have lower educational attainment, have lower health literacy, live below the federal poverty level, and lack health insurance or be underinsured. [Moreno] Latinx individuals also have an obesity rate of 44.8%, compared with a rate of 42.2% among non-Hispanic White individuals. [Serra]

Between 1999 and 2018, 21% of US born Latinx individuals and 32% of foreign-born Latinx individuals had food insecurity. [Pruitt] Information from the US Census Bureau on real median household income by race and Hispanic origin of householder in 2021 shows Asian households to be the highest earners, at $101,400, while Latinx households only earn $58,000. [Srinivasan]

Based on 2023 data, Latinx individuals have the lowest representation quotient of medical students enrolled at US medical schools compared to their corresponding percentage of the US 2023 population (12.7% vs 19.1%). [Franco] Furthermore, only 9% of oncologists are Latinx, and only 1/3 of those are women. Retirement could even make these disparities more pronounced, since 20% of Latinx physicians are over the age of 64. [Rios] Underrepresentation in medical oncology has real-world consequences, with very little improvement in cancer deaths observed among Latinx patients since 1990, in contrast to relatively large improvements for non-Hispanic Black and non-Hispanic White patients. [Rodriguez]

Latinx communities are also disproportionately affected by the cancer-causing effects of climate change in the US, [Ellison] disparities in genetic cancer risk assessment, [Hurtado de Mendoza] inequities in psychosocial care, [Costas-Muñiz] and the difficulties of a language barrier. Language concordance, defined in part by the US Department of Health and Human Services (HHS) as the hiring and equitably supporting of “qualified bilingual and multilingual staff, and staff proficient in American Sign Language (ASL), to provide direct ‘in-language’ communication,” is often lacking. [Martinez]

### Cancer inequity

Cancer is the leading cause of death in the US Latinx population. [Ellison] Every year, approximately 144,154 Latinx individuals are diagnosed with cancer, 18.3% of which are parents of minor children. Of these recently diagnosed parents, 78.9% are female. [Palacios] When compared to non-Hispanic White breast cancer patients, Latinx breast cancer patients tend to be younger, have a higher grade of disease, have a more aggressive disease, and have higher rates of obesity and type 2 diabetes. [Canola] In fact, breast cancer occurs 10 years earlier in Latin American populations when compared with non-Hispanic White populations. [Cabrera] Across the cancer continuum, Latinx patients demonstrate a lower likelihood of having a primary care provider, lower rates of cancer screening, and a greater likelihood of being diagnosed with advanced cancer. Although cancer accounts for one-fifth of deaths among Latinx individuals in the US, Latinx patients remain largely underrepresented in cancer research and cancer clinical trials. [Moreno]

There are significant disparities in cancer screening in Latinx versus non-Hispanic White individuals, many of which are driven by social determinants of health. [Hernandez-Barco] Many of the cancers with the highest incidence and mortality among Latinx individuals are cancers that are known to be positively influenced by engaging in a physically active lifestyle. [Dieli-Conwright] Furthermore, vaccine shortages, accessibility of services, affordability and availability, provider missed opportunities, and difficulties in tracking vaccine administration are all barriers that prevent administration of cancer-preventing vaccines such as the human papillomavirus (HPV) vaccine. [Martinez] Interventions such as smoking cessation programs known to be effective in the general population, are also difficult to tailor to specific Latinx populations. [Cupertino, Tamí-Maury] Text message-based programs may be an effective and adaptable way to engage Latinx smokers. [Chalela]

The COVID-19 pandemic increased the vulnerability of cancer patients, especially in the Latinx community. Cancer deaths among Latinx individuals in the US increased by 11.7% from 2019 to 2023, which contrasts dramatically with the 0.2% decrease in cancer deaths for Black individuals and the 0.9% increase for White individuals. [Sáenz] Cancer screening also decreased during the time of the pandemic, with 1.3 million fewer colonoscopies performed in 2021 than in 2019, for example. [Coronado] Latinx individuals were impacted by COVID outside the US as well; by June 2020, 27% of world deaths from COVID-19 were occurring in Latin America. [Vilar-Compte] The pandemic also caused a critical shortage of research staff, diminishing trial availability and accrual, including for underserved populations, and leading to substantive delays in results reporting. [Doroshow]

Latinx cancer survivors experience a wide range of disparities, including increased use of financial coping behaviors (such as skipping medications) and worse health-related quality of life outcomes compared to non-Hispanic White survivors. [Graves] Healthcare provider communication and availability of care are vital for Latinx patients, who have a lower probability of receiving timely surgical treatment when diagnosed with early-stage breast cancer. [Farias] These patients are also less likely to receive palliative care. [Moreno] Cognitive behavioral therapy (CBT) has been shown to be effective in cancer survivors and in Latinx individuals, however, barriers to care include transportation, health and mobility problems, scheduling, and scarcity of therapists. [Piette]

Although pediatric cancer survival in the US now exceeds 80%, survival disparities exist for Latinx children, who have higher incidence of several cancers, including leukemia and lymphoma, and have lower 5-year overall survival than non-Hispanic White children (74% vs. 81%). [Aristizabal, Grimes] In fact, children living in Latinx enclaves, defined as neighborhoods with a high proportion of Latinx residents, recent immigrants, and linguistically isolated households, have poorer overall survival after diagnosis of acute lymphoblastic leukemia. [Schraw] Latinx children also have more frequent and more severe treatment-related toxicities with several common key drugs utilized in pediatric cancer regimens. [Grimes] Information on Latinx adolescent and young adult (AYA) survivors is lacking, however, due to low clinical trial participation associated with a lack of awareness of clinical trials, fear of toxicities, transportation issues, a lack of access to specialized cancer centers, high rates of uninsured patients, language and communication barriers, and more. [Casillas]

The underrepresentation of Latinx participants in biomedical research is startling. [Adjei] Despite comprising 19% of the US population, Latinx individuals make up only 3.1% of National Institutes of Health (NIH) clinical trial participants nationwide, and 2.7% of US Food and Drug Administration (FDA) novel drug trial participants. [Mendoza] Latinx data is also often disaggregated due to inconsistent definitions and questionnaires. [Marino] In order to fully understand the complexity of the Latinx cancer landscape, an integrated approach is needed, combining clinical and epidemiological data with proteomics, exome sequencing, genome sequencing, structural genomics, functional genomics, epigenomics, and spatial transcriptomics. [Camargo, Velazquez] Although polygenic risk scores can help predict cancer risk, those currently in use are based on European data, and more work is needed to develop polygenic risk scores designed for Latinx individuals. [Fejerman]

These ideas are just some of the topics that were discussed at the 2024 ASCL conference. What follows here are synopses of each presentation, outlining the main ideas put forth by each presenter.

## Aligning Individual- and System-Level Solutions to Address Latino Cancer Inequalities

### Using Science to Address Latino Health Disparities Research

Eliseo J. Pérez-Stable, M.D., is Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH).

*This plenary session occurred at 8:30 am., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

**Health disparities**

Dr. Pérez-Stable began his presentation by discussing populations with health disparities. While race, ethnicity, and socioeconomic status are the fundamental pillars of health disparities science, the intersection of these factors with rural populations, sexual and gender minorities, and people with disabilities are also important to consider. Historically, populations with health disparities have been compared to White populations; however, an effort is being made to establish aspirational goals for all populations based on national metrics, thereby avoiding the assumption that White outcomes are the ideal.

Latin America has been a melting pot of mixed populations for 500 years, with over 20 heritage groups recognized by the Hispanic Community Health Study/Study of Latinos. These groups are distinct, with unique culture, language, and US influence, but are also connected by more similarities than differences. The Office of Management and Budget has even recently proposed to eliminate the two-question approach to identifying race and ethnicity, instead instituting a singular race and ethnicity identifying question with Hispanic/Latino being one of 7 categories to choose from.

Dr. Pérez-Stable and colleagues recently published an analysis of the economic impact of inequities in the US, showing an annual burden of $451 billion based on racial and ethnic minority inequities, and a burden of $978 billion based on education levels of less than a college degree. This cost is based on excess medical care expenditures, lost labor market productivity, and premature death.

**Cancer disparities and community engagement**

Cancer health disparities among the Latino population are variable. Latina women, for example, have the lowest rates of breast and lung cancers, but the highest rate of cervical cancer. Latino men have the lowest rate of lung cancer but a relatively high rate of liver cancer. Reducing these inequities is multifactorial: standardized measurements and questions are needed to ensure Latinos are not underrepresented, big data is needed to facilitate discovery science, diversity of the scientific and clinical workforce should be promoted, community engagement is needed to build trust for sustainable relationships, and what is already known to work needs to be implemented. One solution to the need for standardization of information across scientific studies is the use of the PhenX Toolkit to measure social determinants of health, developed in 2022.

Several principles determine the efficacy of quality community engagement. Research must be initiated in full partnership with community members, scientists, and the government. Scientists must listen to the concerns and problems of the community and decide on a research plan together. The research plan must be sustainable over time, have shared governance, provided tangible financial support, and include a partnership based on trust, mutual benefits, complementary skills, and a focus on health.

Furthermore, to achieve community engaged research, several paradigm shifts are needed. First, the model of care must change to population health built on strong primary care. Second, the importance of health, and not just health care, must be recognized. Community resources must also be engaged in promoting health, including access to real food and safe places. Finally, structural, and interpersonal discrimination should be recognized and managed.

One example of an NIH program working to build trustworthy partnerships is the Community Engagement Alliance (CEAL), which was established during the pandemic and targets underserved communities and racial and ethnic groups. More recently CEAL has shifted to address more general health concerns including maternal health and climate health and is transitioning further to address and reduce health disparities such as those seen in cancer care. Although this effort is limited by funding, capacity, and expertise, a continued focus on sustaining trust can provide an avenue for meaningful research.

### Race and health care

Beyond community engagement, race plays a major role in health care. For example, race may influence patient-clinician communication, which is directly linked to higher patient satisfaction scores, better adherence, and improved health outcomes. African American and Latino physicians care for >50% of minorities, >70% of patients with limited English proficiency, and a disproportionate number of Medicaid/uninsured patients. However, in 2022, only 14% of medical school graduates and practicing physicians were underrepresented minorities.

A 2023 Kaiser Family Foundation survey found that 40% of African American participants, 30% of Latino/Latina participants, and only 6% of White participants reported discrimination in which race or ethnicity was a contributing factor at least three times in the past year. The same survey found that 18% of African American patients, 11% of Latino/Latina patients, and 3% of White patients felt that a healthcare provider or health staff member treated them unfairly or with disrespect because of race or ethnic background over the past 3 years.

Such racism and discrimination affect the Latino population in unique ways. First, Latino Americans have the highest rate of uninsured people in the country, leading to less healthcare access and worse management of chronic conditions. Immigration status is another factor, leading to fear of participating in clinical trials and mistrust in research. A lack of English language proficiency may limit employment options, and accents when speaking English may lead to challenges in understanding. Finally, stereotypical phenotypes of dark skin, non-European features, lower height, and higher BMI affect individual health experiences.

Besides a greater number of Latino clinicians, other solutions may help mitigate this discrimination: greater access to health insurance, care coordination across systems, patient-centered care focused on effective communication and cultural competence, greater equity through electronic health records, and an equity quality measure to gauge performance and risk. With these solutions, along with the NIH programs and the community engaged research mentioned above, the overall health and cancer disparities faced by Latino patients may be reduced.

## The Impact of Climate Change and Natural Disasters Across the Cancer Control Continuum

Dr. Gary L. Ellison is the deputy director of the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI).

*This plenary session occurred at 9:45 a.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

### Government initiatives to decrease cancer deaths and address climate change.

Dr. Ellison began by discussing the gains that have been seen in cancer mortality in the US since 1990, when there were 215 cancer deaths per 100,000, compared with 146 deaths per 100,000 in 2019, an improvement of about 30%. In 2022, President Biden reignited the Cancer Moonshot with the goal of reducing cancer mortality by a further 50% in the next 25 years. The National Cancer Plan is a framework with eight aspirational goals linked to the Cancer Moonshot's target of reducing cancer mortality by 50%. Four of the plan's goals feature prominently in cancer control, and some of the strategies associated with prevention, early detection, and treatment would be supported by the Division of Cancer Control and Population Sciences (DCCPS) with the aim to accelerate progress toward cancer mortality reduction.

On January 27, 2021, the White House issued an executive order on tackling the climate crisis at home and abroad, which established the Office of Climate Change and Health Equity (OCCHE), as well as the NIH Climate Change and Health Initiative. The Climate Change and Health Initiative has developed a strategic framework for approaching climate change that includes partnering with climate and health scholars, as well as emphasizing health effects research, health equity, training and capacity building, and intervention science.

### Climate change and cancer

Rising temperatures, extreme weather, rising sea levels, and increased levels of $CO_2$ have directly impacted human health, leading to increased incidence of heat-related illness, asthma, allergies, communicable diseases, malnutrition, forced migration, and more. The Climate Change and Health Initiative has described needed interventions to combat these changes, including early warning and preparedness, community engagement, targeted prevention and threat reduction, education and awareness raising, and adoption and integration. More research is also needed to understand the full impact of climate change on health.

Climate change also has a direct impact on cancer risk through a number of pathways. Air quality, for example, may be compromised through particulate pollution resulting from wildfires, which causes about 15% of lung cancer deaths and impacts vulnerable cancer survivors. Water pollution may also be affected through fracking, flooding, wildfires, and oil & gas extraction, resulting in contamination with carcinogenic and persistent pollutants. Ozone depletion and ultraviolet radiation exposure have been worsened by climate change, and melanoma incidence is increasing. Finally, food production quality and yields have been negatively impacted by climate change, reducing access to a protective diet for cancer risk and survivorship.

Climate disasters can also disrupt cancer care and lead to workforce and supply shortages. In fact, cancer patients exposed to Hurricane Katrina have been found to have worse long-term cancer survival. Furthermore, lung cancer patients who experience a hurricane disaster during radiation treatment have longer radiation treatment durations and significantly worse overall survival.

**Climate and cancer among Latino individuals**

Latino individuals are the largest and youngest minoritized community in the US, primarily concentrated in the Southwest and Florida. This diverse community generally has a lower socioeconomic status, often stemming from structural racism, and faces barriers to healthcare. Cancer is the leading cause of death in the US Latino population.

Latino communities are also disproportionately affected by climate change in the US; close to 50% live in California, Texas, and Florida and experience an increase in wildfires, drought, extreme heat, hurricanes, sea level rise/flooding, and increased exposure to burning of fossil fuels. Latino individuals are also overrepresented in outdoor industries including agriculture, construction, first responders, and landscapers, and are therefore more likely to lose time working due to increase in high-temperature days. In fact, 81% of Latinos say addressing climate change is top or one of several important concerns, and 71% say it is affecting their local communities.

The priority of the DCCPS is to expand and enhance research to understand and mitigate the impacts of the environment and climate change on cancer across the cancer control continuum. This includes developing novel measures to more accurately measure exposure and risk, supporting research on the effects of climate change on cancer risk, identifying research infrastructure needs, developing and implementing routine surveillance, supporting research that has an impact on health equity, and achieving better collaboration and coordination with internal and external partners.

1 National Cancer Institute. National Cancer Plan. Accessed August 3, 2024. https://nationalcancerplan.cancer.gov/

2 US Environmental Protection Agency. Climate and social vulnerability in the United States; Pew Research Center. September 2021. Accessed May 4, 2024. https://www.epa.gov/system/files/documents/2021-09/climate-vulnerability_september-2021_508.pdf

## Making the Case: Cancer in Latinos is a Public Health Crisis

*This breakout session occurred at 10:45 a.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

### Structural Determinants of Health Impacting Latino Cancer Health Disparities: Genetic Cancer Risk Assessment

Dr. Alejandra Hurtado de Mendoza is an Assistant Professor at the Cancer Prevention and Control Program at Georgetown Lombardi Comprehensive Cancer Center.

**Disparities across the continuum**

Dr. Hurtado de Mendoza's presentation focused on disparities in genetic cancer risk assessment, multi-level barriers that Latinos face across the genetic cancer risk assessment continuum, and an example of a multilevel intervention to decrease disparities. The presentation began by discussing how disparities in the genetic cancer risk assessment continuum begin with awareness. Only 23% of Latino individuals were aware of cancer genetic testing in 2020, compared with 26% of Black/African American individuals and 42% of Non-Hispanic White individuals. Further evaluation showed that awareness of genetic testing was associated with higher household income and level of education.

Beyond awareness, screening and referrals are the next steps in the genetic cancer risk assessment continuum. One recent systematic literature review characterized strategies to identify at-risk individuals outside specialty settings and described the extent to which these strategies have extended the reach of genetic services to underserved target populations. In this nascent area of research, the review found that most interventions used brief screening tools plus institutional support. Although the findings were promising in terms of expanding the reach of cancer genetic services, there is limited research on the barriers to and facilitators for implementation. In addition, little is known about the scaling of these strategies.

Disparities in genetic counseling and testing are often rooted in access, with cost being a limiting factor for many patients. The scarcity of Spanish-speaking genetic counselors also contributes to these disparities, with the language barrier leading to frequent miscommunications. One potential solution may be alternative delivery models such as genetic counselor extenders (e.g. group counseling), telephone genetic counseling, and patient-facing materials such as brochures and websites.

Disparities in follow-up risk management are also a factor. Current translational genetics research focuses primarily on utilization of genetic testing, and inequities in this area. However, it is vital to address barriers to downstream care especially for patients from underserved groups. This means consideration of barriers at the health system-level, clinician-level, and patient-level.

**An educational video**

One example of a multilevel intervention to decrease disparities involves recent research by Dr. Hurtado de Mendoza and colleagues. As part of the work, interviews with providers and at-risk women revealed both barriers to (health care access, low awareness) and facilitators for (education on how testing can inform family risk and treatment and prevention decisions) genetic counseling and testing. In partnership with academic institutions, artists, and community based organizations, an educational video was developed in response to this formative work.

A single arm pilot study was then conducted assessing the video's effectiveness. Results of the pilot showed statistically significant increases in knowledge (p<.001), intentions (p=.001), positive attitudes (p=.04) and emotions (p=.04) towards genetic counseling and testing. Furthermore, participants reported high satisfaction with the video, with 67% attending genetic counseling.

Following the single arm pilot study, a randomized controlled trial called the CONTIGO study was initiated with the aim of assessing the efficacy of the culturally targeted narrative video in enhancing genetic counseling and testing uptake, compared with a fact sheet. The study also seeks to assess the barriers to and facilitators for implementing hereditary breast and ovarian cancer (HBOC) screening tools at community based organizations. The study aims to recruit 300 at-risk Latina participants to randomize them into a video arm (n=150) and a fact sheet arm (n=150). Two-week follow-up surveys and four-month follow-up surveys are planned.

### Telephone counseling and future work

Telephone genetic counseling (TGC) can be an alternative strategy to enhance reach and access to genetic counseling and testing. TGC is safe, acceptable, effective, and less costly than in-person genetic counseling. It also reduces logistic barriers and can facilitate access to Spanish-speaking counselors. However, studies show that TGC can lead to lower testing uptake compared to in-person genetic counseling, especially in patients from minority groups, patients with high distress and risk perceptions, or those with a lower education.

Future work in this area involves the assessment of barriers to and facilitators for the completion of genetic testing in response to telephone genetic counseling. Dr. Hurtado de Mendoza and colleagues also plan to refine culturally targeted materials and develop a community based organization toolkit that helps employees navigate genetic counseling and testing and provides them with risk management tools. Partnership with advocacy organizations will be a priority throughout these efforts.

## The Critical Role of Language in Latino Cancer and Health Outcomes

Dr. Glenn A. Martinez is the Dean of the College of Liberal and Fine Arts, Professor of Spanish Bicultural/Bilingual Studies and Public Health, and Stumberg Distinguished University Chair at the University of Texas San Antonio.

### Language Concordance

Dr. Marinez's presentation covered 4 main topics: language concordance and the promise of "direct in-language communication" for Latino health, language concordance and cancer, the National Association of Medical Spanish, and the Physician Oral Language Observation Matrix (POLOM). The presentation began by discussing language concordance and its impact on Latino health. According to the US Department of Health and Human Services (HHS), part of language concordance is the hiring and equitably supporting of "qualified bilingual and multilingual staff, and staff proficient in American Sign Language

(ASL), to provide direct ‘in-language’ communication.”

Language concordance offers many advantages, including improved quality of care, with patients that are less likely to feel confused and frustrated, and greater patient satisfaction. Likewise, health outcomes are positively affected, with improvements noted in glycemic control, medication adherence, and understanding of medication and dosage. Finally, relationship factors are impacted by language concordance, with greater agreement with physician recommendations, more questions asked by the patient, and greater disclosure of sensitive information.

In the specific area of cancer in Latino patients, language concordance also plays a major role. Although language concordance seems to have no effect on the likelihood of Spanish speakers to obtain screening, it is associated with timelier resolution of abnormalities within 90 days. Furthermore, language concordance is associated with greater communication of biomedical information from providers, and greater agreement among patients. Finally, language concordance is associated with more general satisfaction among cancer patients, improved perceived interpersonal skills of the care team, and greater time spent with patients.

### The National Association of Medical Spanish

In light of these improved outcomes, it is imperative to build a pipeline of Spanish-speaking providers to address cancer in Latinos. The National Association of Medical Spanish was formed in response to this need. Although the association is composed of physicians, professors, and other professionals, the largest portion of members (44%) are medical students. This infusion of youth in the area of language concordance provides hope for the future of Spanish-speaking medical professionals.

Several core competencies were proposed by the Association at the Medical Spanish Summit. First, fluency in Spanish is not sufficient for medical professionals; medical Spanish knowledge regarding organ systems and common disease entities are also needed. Second, providers must be able to provide patient-centered explanations of medical diagnoses and treatment plans. Finally, providers must achieve a self-assessed confidence that allows them to have meaningful patient interactions.

Many collaborators have made key contributions to the foundation of the National Association of Medical Spanish, including Drs. Glenn Martinez, Alyssia Miller De Rutte, Pilar Ortega, Marco Aleman, Alejandra Zapien Hidalgo, Cristina Perez-Cordon, Robert Mueller, Karol Hardin, Lisa Diamond, and Norma A. Perez.

### The Physician Oral Language Observation Matrix

Another tool for the advancement of language concordance is the Physician Oral Language Observation Matrix (POLOM), which is a rater-based tool for assessment of medical oral language skills as contextualized for patient care. This matrix provides a way to reliably evaluate whether a physician is ready to perform their patient care responsibilities in a non-English language. The goal of the POLOM is to improve health outcomes and satisfaction for patients, to support multilingual physicians and enhance wellbeing, and to address patient communication aspects of all medical specialties.

The six categories assessed by the POLOM are comprehension, fluency/fluidity, vocabulary, pronunciation, grammar, and communication. Each category is rated on a scale of 1 to 5. Level 5 for comprehension, for example, indicates that the candidate understands conversation at normal speed without difficulty. Occasional requests for clarification of regionalisms, or repetition of the same word or phrase, may be acceptable in the context of overall excellent comprehension for Level 5.

With organizations like the National Association for Medical Spanish, and tools like the POLOM, the future of language concordance looks somewhat brighter. This future may be filled with better provider-patient communication, leading to greater trust and more positive patient outcomes.

## Access to Psychosocial Care for Latinos in the US and Latin America

Dr. Rosario Costas-Muñiz is Assistant Attending Psychologist in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center.

### Psychosocial Care for Latinos

Dr. Costas-Muñiz's presentation began by focusing on several key messages:

- "Psychological and social problems created or exacerbated by cancer - including depression and other emotional problems; lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family life - cause additional suffering, weaken adherence to treatments, and threaten patients' return to health."
- Latinos have a different pattern of access, use, and availability of psychosocial services and face unique challenges in accessing psychosocial care.
- Psychosocial oncology is either not established or not completely established, or not an integral part of cancer care for Latino patients in many countries, especially developing nations, where basic care is sometimes not provided to cancer patients.
- Interventions for Latino cancer patients are being developed, adapted, tested, and studied, but they need to be developed or adapted with a cultural, linguistic, and contextual lens, drawing from intervention development, cultural adaptation, and implementation and dissemination science.
- Professional networks like the Formación de Investigacion Psicosocial Oncológica Latinoamenricana (FIPOL) network can promote the field by implementing initiatives in capacity building, research collaborations, resources development, and science dissemination and communication.

Mental health and distress screening and management is mandated or recommended by several organizations, including the National Comprehensive Cancer Network (NCCN), the American Society of Clinical Oncology (ASCO), and the International Psycho-Oncology Society (IPOS) Standard on Quality Cancer Care. However, studies have shown that racial and ethnic minority (REM) patients in the US show significantly worse depression than non-Hispanic White patients. Those with limited English proficiency and lower income are at even higher risk. Furthermore, REM patients are less likely to receive psychological or psychiatric services and interventions.

A recent study published by Dr. Costas-Muñiz and colleagues assessed a sample of 265 Latina and non-Latina White women who received treatment in a comprehensive cancer center in New York City. A similar proportion of both cohorts expressed a need for mental health, discussed this need with their cancer care provider, and received a referral. However, significantly fewer Latina patients had contact with a mental health professional, received psychosocial services, had contact with social workers, or received psychotropic medication.

The greatest barrier to psychosocial care was the desire to return to normal. Patients who reported this desire had less access to mental health therapy, either individual or group therapy, and had fewer contacts with mental health providers. Other barriers included not understanding the benefits of mental health therapy, not knowing where they can receive services, stigma about mental health, the belief that it is normal to have emotional discomfort, the belief that providers will not understand cultural background or values, and feeling uncomfortable with interpreters, if necessary.

### Interventions for Latino Cancer Patients

Dr. Costas-Muñiz and colleagues are also currently conducting a systematic review of studies evaluating interventions for Latino cancer patients. Of over 13,000 titles reviewed, 140 have been included in the study and discuss interventions such as cancer education, palliative care, exercise or nutrition, relaxation techniques, parenting intervention, multimodal intervention, medication, survivorship care plan, cognitive behavioral therapy (CBT), and cognitive behavioral therapy for insomnia (CBT-i).

A great need exists to support these interventions in the context of psycho-oncology care for Latino cancer patients, caregivers, families, and community members. This support should come in the form of policy changes, evidence-based practice guidelines and recommendations, training for providers and researchers, and research collaboration.

### FIPOL

In response to this great need, in 2017, the Formación de Investigacion Psicosocial Oncológica Latinoamenricana (FIPOL) was founded to connect clinicians, educators, and researchers from Latin America and Spanish-speaking countries interested in psychosocial oncology, behavioral medicine, and palliative care. FIPOL's unique approach is centered in interregional collaboration with the aim of psychosocial oncology capacity building. Activities include hosting seminars and courses, developing collaborative research projects and programs, disseminating psychosocial oncology research, and distributing information about training opportunities, collaborations, and developments in the field.

Several lessons have been learned through this important collaboration. First, there is a need for further development, study, and cultural adaptation of interventions in the oncological context for patients, survivors, and caregivers/family members. Second, greater access to training and clinical and research resources is needed. Finally, there is a need for validated instruments and/or having access to validated instruments in the context of cancer to support clinical work and research. FIPOL has already begun to develop tools to address these important needs.

# COVID 19: Implications on Cancer Prevention, Treatment and Care for Latinos

*This breakout session occurred at 10:45 a.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

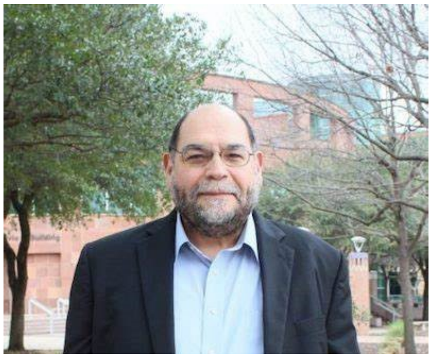
## Cancer Deaths Among Latinos in the COVID-19 Era: National and State Trends

Dr. Rogelio Sáenz is Professor of Sociology and Demography, Dean of the College of Public Policy, and holds the Mark G. Yudof Endowed Chair at the University of Texas at San Antonio.

### COVID-19 vulnerability

Dr. Sáenz's presentation began by discussing the vulnerability of people with cancer in the COVID-19 era. Over the last four years, a significant amount of research has observed the negative impact of COVID-19 on the survivability of people with cancer, along with rising numbers of cancer incidence and death due to disrupted health care. The growing Latino population is particularly vulnerable, experiencing increased incidences and death associated with cancer, low access to health care, frequent existing comorbidities, and elevated COVID-19 death rates, and many work as essential workers.

Although there is currently limited information about changes in Latino cancer mortality in the COVID-19 era, cancer patients are at a higher risk of contracting COVID-19 due to compromised immune systems. They also experience changes in cancer treatment with greater need for virtual sessions. Changes in annual checkups and regular medical visits include delays in cancer screening, diagnosis, and treatment. These changes led to lower cancer incidence and deaths reported in 2020, followed by increases in 2021 and subsequent years. Furthermore, evidence now suggests that COVID-19 could "create a microenvironment that may support cancer cell proliferation and induce the activation of dormant cancer cells."



### Demographic insights into cancer death rates

Recent research by Dr. Sáenz and colleagues revealed that cancer deaths among Latino individuals in the US increased by 11.7% from 2019 to 2023. This is in contrast with a 0.2% decrease for Black individuals and 0.9% increase for White individuals. Because the Latino population is overall younger than the national average, an age-adjusted death rate (AADR) was also calculated. The change in AADR for the Latino population from 2019-2023 was a 1.0% increase, compared with a 4.7% decrease for the Black population and a 1.6% decrease for the White population.

The leading types of cancer deaths among Latinos were also ranked by percent change in deaths from 2019 to 2023. The cancer with the highest percent change in that time span was malignant neoplasm of the rectum, which showed a 32.0% increase in cancer deaths. The next highest cancers on the list were malignant neoplasm of the uterus, intrahepatic bile duct carcinoma, malignant neoplasm of the endometrium, and malignant neoplasm of the kidney.

When assessed based on urbanization category, Latino cancer death rates increased the most in medium metro areas, a total increase of 9.3% from 2019 to 2023. The rates increased only 4.9% in small metro areas, which represented the smallest increase in the categories studied. Other categories included large central metro, large fringe metro, micropolitan (nonmetro), and noncore (nonmetro).

At the state level, the cancer AADR among Latinos from 2019 to 2023 was highest in New Mexico, followed by Florida. Of the 12 states with the highest cancer AADR, 9 were also among the 12 states with the highest COVID-19 AADR, showing a high correlation between the two conditions. The states with the lowest cancer AADR among Latinos were Iowa, Alabama, Arkansas, Oklahoma, and Mississippi. Interestingly, these states are considered “Latino new-destination areas”, meaning the Latino population has increased in these states only in the last few decades. These populations tend to be younger, and predominantly immigrant.

From 2021 to 2023, 75.6% of states with the required data showed an increase in Latino cancer AADR. Only 64.7% of states had increases in White cancer AADR in that time frame, and 53.7% of states had increases in Black cancer AADR.

## Closing remarks and limitations

The results of the analysis presented by Dr. Sáenz showed that Latino populations experienced increases in cancer deaths and cancer AADR during the pandemic era. Although a dip in Latino deaths was observed in 2020, a corresponding increase in death rates was observed in 2023 at the national level and across the states. The pandemic revealed even more starkly the inequities that exist in access to health care.

Some limitations existed in Dr. Sáenz work. For example, the data for 2022 and 2023 are provisional. Also, possibilities exist for misclassification of race/ethnicity and underlying causes and contributing causes of death. Furthermore, there is a lack of data to assess nativity variations among cancer deaths before and after the COVID-19 era. Finally, the mortality increase due to rising cancer deaths associated with the rapidly growing Latino population cannot be disentangled from deaths associated with influences of the changing COVID-19 environment, which increased vulnerability among people with cancer. Still, the use of AADR as a parameter for measuring mortality may address some of that confounding effect.

## COVID-19's Influence on Colorectal Cancer Screening in Latino Communities: The Role of Mailed Fecal Test Outreach

Dr. Gloria Coronado is Associate Director of Population Science at the University of Arizona (UA) Cancer Center and Professor in the UA College of Public Health.

### Colorectal cancer screening and COVID-19

Dr. Coronado's presentation discussed the impact of COVID-19 on colorectal cancer screening and follow-up; she presented findings of her research using health record data and qualitative interviews with clinic staff at the nation's largest federally qualified Health center. In 2020, modeling data suggested that cancer care reductions due to the pandemic would have profound long-term impacts, resulting in over 57,000 missed diagnoses and 10,000 excess deaths from cancer over the next decade. This modeling did not consider the specific impact that these cancer care reductions might have on underserved populations.

In response to this modeling, Dr. Coronado and colleagues partnered with the AltaMed Health System, a large federally qualified health center, to provide evidence of the impact of cancer care reduction on the Latino community. AltaMed had 245,012 patients in 2022, 93% of which were a racial and/or ethnic minority, and 85% of which were Latino. The health center also employs over 3,000 employees and 400 physicians. Their mission is to eliminate disparities in health care access and outcomes.

Overall, in national data, colorectal cancer screening increased from 2019 to 2021, indicating a robust rebound after the pandemic. However, this increase was entirely driven by increases in stool testing; there were 3.6 million more stool tests in 2021 than in 2019. Colonoscopies, however, decreased in this time frame, with 1.3 million fewer in 2021 than in 2019. Interestingly, this increase in colorectal screening was entirely driven by increases in screening on the West coast. These findings indicate that home-based testing may be key to maintaining screening levels during health care disruptions. One problem with this trend, however, is that only 57% of patients with positive stool sample tests obtain a follow-up colonoscopy within 1 year. A colonoscopy is needed to find early forms of cancer or to find and remove small growth (polyps) to prevent cancer from occurring.

When comparing data from the Behavioral Risk Factor Surveillance System (BRFSS, a nationwide database) with data from the Uniform Data System (UDS, which only includes federally qualified health centers and therefore more underrepresented populations), colorectal cancer screening numbers are vastly different. In fact, compared with BRFSS data, the UDS data shows a 30% lower colorectal screening rate in 2020.

### RESTORE

Dr. Coronado and colleagues recently initiated a study called RESTORE, funded by the National Cancer Institute, assessing the long-term impacts of the COVID-19 pandemic on disparities in cancer screening and follow-up. This collaborative effort with AltaMed, RAND corporation, and the Kaiser Permanente Center for Health Research, aims to assess trends in screening and follow-up for colorectal, breast, and cervical cancers; assess long term impacts of COVID on colorectal cancer outcomes; and identify organizational-level barriers and facilitators.

Monthly colorectal cancer screening rates were evaluated during 3 time periods: pre-pandemic (March 2018-March 2020), pandemic (March 2020-December 2020), and vaccination era (January 2021-July 2022). Over 60,000 patients over the age of 50 were evaluated, 79% of which were Hispanic/Latino. Predictably, during months when mailed outreach was sent out encouraging a fecal immunochemical test (FIT), rates were higher. If these months were excluded, screening rate trends were shown to decrease during the pandemic time period. However, if data from the mailed FIT outreach was included, decreases in screening rates were mitigated. This indicates the potential utility of mailed outreach programs during national natural disasters.

### Qualitative Interviews

Qualitative interviews by the RESTORE team revealed some broad impacts of the COVID-19 pandemic on cancer care. First, AltaMed clinical teams expressed being “over-run” by upper respiratory infection and COVID needs, meaning they had no time for routine and preventive care. Furthermore, no infrastructure was in place for telehealth, creating an enormous learning curve for both staff and patients. Prior disaster planning was oriented for short-term, episodic issues (e.g., winter flu, TB outbreak) and not designed for a long-term, multi-year pandemic. Finally, pre-pandemic cancer screening goals followed “year-long roadmaps;” during the pandemic screening just “happened on the side” when it was feasible according to surges and access/capacity.

Colorectal cancer screenings specifically were delayed while providers focused on patients with COVID, those with complex chronic or acute needs, and COVID tests and vaccines. Colorectal cancer awareness and education campaigns were paused. Because of the move to telehealth, fewer FIT kits were distributed during point-of-care visits, less education happened during visits, and patients wanted less information on preventive care during telehealth visits.

Lessons learned from the pandemic included the importance of being nimble and resilient, incorporating more long-term disaster planning approaches, the use of telehealth, and improving data tracking tools. Some concerns remain, including the cancer diagnoses that were missed during the pandemic, limited staffing capacity, and the social determinants of health of cancer patients. However, mailed FIT outreach, the promise of telehealth, and improved local systems for monitoring infectious diseases represent opportunities for resilience.

## Cancer Patients at an Oncology Center in Mexico: Navigating COVID-19 in an Underfunded Health System

Dr. Diana Vilar-Compte is a Professor in the Department of Infectious Diseases at the Instituto Nacional de Cancerologia in Mexico.

### COVID-19 and cancer in Mexico

Dr. Vilar-Compte’s presentation began by discussing healthcare conditions in Mexico at the start of the COVID-19 pandemic. According to the Organization for Economic Co-operation and Development (OECD), Mexico’s investment in healthcare is one of the lowest in the world. Government healthcare spending was only 585.5 US dollars per capita per year, which translates to only 40% of healthcare delivery being funded by the public sector. The private sector, therefore, played a key role in delivering healthcare during the pandemic, and, therefore, access to healthcare for some patients was limited due to cost.

In 2004, a program called Seguro Popular was implemented in Mexico which helped mitigate inequities in cancer care. However, in November 2019, just months before the pandemic, Seguro Popular was replaced by Instituto de Salud para el Bienestar (INSABI), a program intended to provide universal health coverage but which was plagued with problems. Because of low investment, a fragmented healthcare system, and overall corruption, 28.2% of the Mexican population (20.2 million people) did not have access to health services, and 40% had severe limitations to essential services in 2020.

Wide socio-economic and education disparities exist in Mexico, similar to other countries in Latin America, where cancer patients face innumerable barriers. Limited access to health care, resource-limited healthcare systems, forced transitions of oncology practices, and changes in treatment decisions are just a few barriers faced by cancer patients in Latin America.

This situation was made worse by the pandemic. By June 2020, 27% of world deaths from COVID-19 were occuring in Latin America. Furthermore, Mexico and Brazil had seen the highest death toll behind only the US. By the end of 2023, there had been over 7.7 million confirmed COVID-19 cases in Mexico, and over 300,000 confirmed deaths. Excess deaths have also been comparatively high in Mexico, indicating difficulties in treating chronic conditions such as cancer and cardiovascular disease.

### Instituto Nacional de Cancerologia

Dr. Vilar-Compte works at Instituto Nacional de Cancerologia (INCan), a hospital in Mexico City that is an important provider of cancer care. With a 133-bed academic cancer center, INCan provided 4,700 surgeries, 52,000 ambulatory chemotherapies, and 212,523 outpatient visits in 2020. In March and April of 2020, INCan became a hybrid hospital to help with the pandemic. However, immediate problems surfaced, including a shortage of healthcare workers and ineligibility for emergency funds due to INCan's lack of qualification as a COVID-19 dedicated hospital.

The median age of cancer patients with COVID seen at INCan in 2020 was 55 years; 31% of patients were obese and 22% had diabetes. The most common cancer seen in 2020 was breast cancer, followed by lymphoma and cervical cancer. Advance stage cancer (stage 3 or 4) was observed in 49% of patients. Of the patients with COVID-19 and cancer seen at INCan, 46% were hospitalized, 22% of which were given mechanical ventilation, and 55% of which died. These numbers were similar to other cancer institutions treating COVID-19, even though many patients presenting to INCan already had severe disease, with 35% of patients having oxygen saturation less than 90% at first medical evaluation.

Because of the combination of COVID-19 and cancer, the change in healthcare policy in Mexico, and changes in treatment decisions, breast cancer patients had many difficulties. A case-cohort analysis of 2,117 patients in 2020 and 2021 revealed that the number one reason for treatment change among chemotherapy and hormone therapy patients was unavailability of medication.

Although 9 different COVID-19 vaccines were approved in Mexico, only healthcare workers and patients over 60 years of age were prioritized. Cancer patients were not prioritized to receive early vaccination nor to receive any specific type of vaccine. Furthermore, updated vaccines were not approved until December of 2023, with no government acquisition mitigating cost, and still with no policies for high-risk groups.

In short, patients with cancer continue to be a high-risk group for developing severe COVID-19 and related sequela. Cancer patients in public hospitals in Mexico continue to face a high burden of the disease and multiple barriers to effective healthcare. Clear policies and access to vaccination and antivirals should be prioritized for all cancer patients.

## Coordinated and Comprehensive Survivorship Care for Latinos

*This plenary session occurred at 1:45 p.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

---

### Latino Cancer Survivors' Quality of Life and Survivorship Care

Dr. Kristi D. Graves is a tenured Professor of Oncology, Cancer Prevention and Control Program leader at the Lombardi Comprehensive Cancer Center, and Associate Dean for Faculty Development at Georgetown University Medical Center.

**Latino cancer survivorship**

Dr. Graves's presentation began by discussing cancer survivorship across the cancer continuum. The National Cancer Institute's (NCI) Office of Cancer Survivorship states that "an individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals."

Latino and Black survivors experience a wide range of disparities, including increased use of financial coping behaviors (such as skipping medications) and worse health-related quality of life (HRQOL) outcomes compared to non-Hispanic White survivors. Potential solutions to these disparities include partnerships with community outreach and engagement programs, local community-based organizations, community health educators, promotoras, and patient navigators.

The American Association for Cancer Research describes three phases of cancer survivorship: acute survivorship, consisting of the time of cancer treatment; extended survivorship, describing the months immediately following cancer and treatment; and permanent survivorship, which encompasses the long-term effects of cancer and treatment. Dr. Graves and colleagues have initiated interventions at each of the three phases of cancer survivorship.

**The ÁRBOLES Familiares Training Program**

Dr. Graves's work on acute survivorship focuses on identifying high risk Latina survivors. Through partnerships with community health educators, the ÁRBOLES Familiares Training Program, co-led by Dr. Susan Vadaparampil, was initiated to address disparities in awareness and uptake of genetic risk assessment among Latinos. The program's goal was to improve trainees' knowledge and confidence about cancer genetics and hereditary breast and ovarian cancer (HBOC) by providing skills for identification of individuals at high risk, referral and navigation of appropriate patients to genetic services, and communication about cancer risk.

Trainees included community health workers and educators, promotoras, lay health advisors, and patient navigators. All trainees were bilingual in English and Spanish, engaged with the Hispanic/Latino community, and interested in learning about increased cancer risk and HBOC. One of the training components was the development of an action project by each trainee. These action projects included educational flyers, presentations, resource lists, information guides, and more. These projects focused on the accurate distribution of information about HBOC, genetic counseling, genetic testing, and family history.

This project shows the utility of community health workers and promotoras in bridging the gap between Latinos at high risk for HBOC and genetic services. Future work in this area could explore the effect of the trainees' action projects on community members' uptake of these services.

### MY-Health study

Dr. Graves's work on the extended survivorship phase of cancer survivorship considered quality of life by country of origin. It is imperative that Latino cancer data become disaggregated to more accurately understand cancer survivorship in Latino subpopulations. To address this concern, a cohort of 5,366 cancer survivors were enrolled between 6 and 13 months after diagnosis in the MY-Health cohort (co-led by Dr. Arnold Potosky and Dr. Carol Moinpour). Quality of life was measured using the Patient Reported Outcomes Measurement Information System (PROMIS) short forms to discern if HRQOL differs by survivors' country of origin after accounting for clinical, demographic, and structural determinants of health variables.

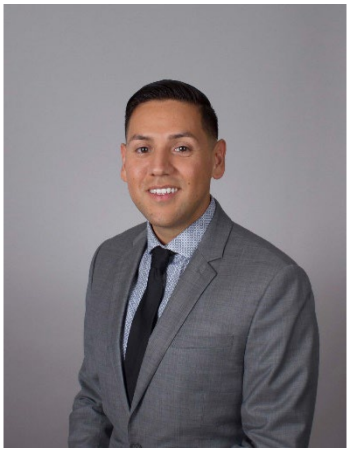
A disproportionately high percentage of Latinos from the Caribbean (Puerto Rico, Cuba, and Dominican Republic) fell into the very low HRQOL category, while a high percentage of Mexican and other Hispanic survivors fell into the low HRQOL category. This inequity shows the importance of early identification of cancer survivors most at risk for very low HRQOL in order to initiate interventions and symptom management. Future work to evaluate the use of HRQOL screeners to promote timely referral for linguistically and culturally-relevant survivorship care may be useful.

### Self-acupressure

The work done by Dr. Graves on the permanent survivorship phase of cancer survivorship involves adapting evidence-based symptom management interventions for Latina survivors. In partnership with Dr. Judy Wang, a pilot study has been undertaken to assess the usefulness of self-acupressure, which has shown promising results in Chinese American breast cancer survivors. The stimulation of acupoints triggers the hypothalamic-pituitary-adrenocortical axis in order to influence sympathetic and peripheral nervous system function. It can also be performed at home for no monetary cost. A video was culturally and linguistically adapted for Black and Latina breast cancer survivors and the pilot study is currently underway, and results are pending completion.

Interventions at each stage of cancer survivorship are vital for addressing disparities among Latino survivors. Furthermore, the disaggregation of Latino cancer survivorship data is imperative to fully understand outcomes among different groups of Latino survivors. Evidence-based strategies must be adapted to reduce disparities in symptom burden among Latinos, and investment must be made in cancer survivorship research, community partnerships, training, and diversifying the cancer survivorship research and clinical workforce.

# Impact of Patient-Centered Care and Care Experiences for Latino Cancer Survivors



Dr. Albert Farias is Assistant Professor of Population and Public Health Sciences at the Keck School of Medicine at the University of Southern California.

## Latino experiences of cancer care

Using data from the California Cancer Registry, Dr. Farias and others have found that certain racial/ethnic groups, including Hispanics/Latino patients, have a lower probability of receiving timely surgical treatment when diagnosed with early-stage breast cancer. It is known that receiving timely evidence-based cancer treatment is vital to reducing disparities in cancer mortality. Why these disparities exist, especially in light of novel therapies being developed, is an important question to consider.

To answer this question, Dr. Farias and colleagues have taken a sequential mixed methods approach to understanding the voices of Latino cancer patients. By asking a racially diverse group of cancer patients about their experiences with cancer treatment, it was discovered that how doctors talk to patients matters. Furthermore, not only did interactions with providers affect the experience of cancer treatment, but also interactions with front office staff, being able to contact someone during off-peak hours, and the physical location and cleanliness of the treatment facilities.

The gold standard for quantitatively measuring these experiences with healthcare is the Consumer Assessment of Healthcare Providers and Systems (CAHPS). The CAHPS program was founded in 1995 and was constructed through a collaborative process which included literature reviews of patient experiences, focus groups with patients, and mining existing patient experience surveys. The result was a patient experience survey that had limited subjectivity, minimal measurement error, standardized measures, and actionable and time-specific data.

Three specific care experiences that have been identified as most important for Latino patients are physician communication, getting care quickly, and getting needed care. These composite measures are derived from a series of individual questions that ask the patients to respond with “never,” “sometimes,” “usually,” or “always.” For example, a patient might be asked, “In the last 6 months did the doctor show respect during your interaction?” Scores range from 0-100 for each care experience, with 90-100 indicating an excellent experience.

Although CAHPS measures are currently used in quality improvement, public reporting, certification and recognition, value-based purchasing, and health services research, they have not yet been used to measure healthcare delivery approaches for underserved populations. In fact, very few studies have been conducted identifying the relationship between patient experiences with care and care outcomes.

## A systematic review and conceptual model

Dr. Farias and colleagues have developed a conceptual model based on a systematic review of the literature. This model reveals that how patients are treated may impact the care that is received by patients, or clinical health outcomes. In order to test the hypothesis that patient experiences with care across domains are associated with receipt of evidence-based care, the population based SEER-CAHPS dataset was used.

The first question posed was whether Latino disparities existed in patient experiences with care. Although disparities based on race/ethnicity in patient experiences with healthcare customer service prior to diagnosis were not observed, disparities between Latino patients and non-Hispanic White patients were significant in the experience of getting needed care prior to diagnosis. In fact, when measures were considered by cancer type, the mean difference in the ability to get needed care was significantly lower for Latino breast and colorectal cancer patients compared to non-Hispanic White patients prior to diagnosis. Disparities were also present after diagnosis, with significant differences observed in the ability to get needed care between Latino and non-Hispanic White patients.

When assessing whether these disparities in patient experiences with care would affect receipt of guideline-concordant cancer treatment, it was found that colorectal cancer patients who had excellent experiences (scored 90 or above) in the measures of getting care quickly, getting needed care, and physician communication had a higher likelihood of receiving guideline-concordant care. In fact, patients with excellent experiences in getting care quickly had 25% greater odds of receiving stage-specific guideline-concordant cancer treatment, with similar associations observed with the other CAHPS measures.

Interestingly, if Latino and non-Hispanic White patients with excellent reports of getting care quickly and getting needed care were considered separately, Latino patients were actually more likely to receive stage-specific guideline-concordant colorectal cancer treatment. This highlights the exciting possibility that ensuring excellent experiences with care for Latino cancer patients could minimize treatment disparities. Therefore, directing resources towards improving Latino patient experiences with care is a step towards achieving cancer healthcare equity.

## Patient Activation and Palliative Care among Hispanics/Latinos with Metastatic Cancer

Dr. Patricia I. Moreno is Assistant Professor in the Public Health Science Department at the Miller School of Medicine at the University of Miami.

**Latino patients and metastatic cancer**

Dr. Moreno's presentation began with an overview of the Latino community in the US. Latino individuals comprise 19% of the population in the US, making Latinos one of the largest and most rapidly growing racial/ethnic minority groups. In fact, the Latino population is projected to account for more than half of the overall growth in the US through 2060. Compared to non-Hispanic White individuals, Latinos are more likely to have lower educational attainment, have lower health literacy, live below the federal poverty level, and lack health insurance or be underinsured.

Across the cancer continuum, Latino patients demonstrate a lower likelihood of having a primary care provider, lower rates of cancer screening, and a greater likelihood of being diagnosed with advanced cancer. Although cancer is one of the leading causes of death among Latino individuals in the US, accounting for one-fifth of deaths, Latino patients remain largely underrepresented in cancer research and cancer clinical trials.

Taking a look now at the unmet needs of patients with metastatic cancer, a 2022 US study found that there were 623,405 patients living with the 6 most common metastatic cancers and projected that number to increase to 693,425 by 2025. These patients are highly underrepresented in clinical trials and have distinct survivorship needs, including the following: cumulative burnout and toxicities related to continuously undergoing cancer treatment, uncertainty and anxiety scan-to-scan regarding response to cancer treatments, coping with loss and end-of-life concerns, diagnosis-related stigma and social isolation, misconceptions regarding metastatic cancer, and the need for community.

### Palliative care

Specialty palliative care teams are led by board-certified palliative medicine physicians who care for patients with serious illness and aim to manage symptoms, manage functional limitations, improve quality of life, clarify treatment goals, and facilitate decision-making and transition care. Although outdated models of care only incorporated palliative care at end of life, after disease-modifying treatment is no longer available, newer evidence-based models emphasize its integration earlier in the disease course in the ambulatory setting in order to proactively prevent unnecessary suffering.

Early integration of palliative care in patients with metastatic cancer improves outcomes throughout the disease course by increasing quality of life and satisfaction with care, while decreasing symptom burden, hospital admissions, emergency visits, and healthcare costs. According to the World Health Organization (WHO), assessment of physical symptoms and psychosocial concerns is a defining component of palliative care. However, best practices to screen and identify cancer patients with complex needs who would benefit from palliative care have not been established.

Relative to non-Hispanic White patients, Latino cancer patients with metastatic cancer experience worse quality of life and symptom burden following diagnosis and treatment of cancer. They are also less likely to receive palliative care, yet very little is known about facilitators and barriers to palliative care among Latino patients or how to empower Latinos in conversations about palliative care.

Latinos experience particular palliative care needs: frustration and ambivalence regarding who should address new or worsening symptoms and side effects of a cancer therapy, the need for prognostic information and communication with the care team regarding prognosis, feeling overwhelmed by treatment decision-making and weighing available options, and fear of loss of control and end-of-life concerns. Certain beliefs about palliative care may act as barriers to care: it is the care that immediately precedes hospice, it is the same as hospice, it is only for pain management, it is for quality of life at end of life, it is only if there are no other options left. Furthermore, many Latino patients have never heard of palliative care.

The preferred approach to palliative care is patient-centered with a needs-based approach, systematically identifying patients who are likely to benefit from palliative care through screening, deploying care in response to their symptoms and supportive care needs, and proactively avoiding symptom crises and improving quality of life. Implementing routine patient reported outcomes (PROs) in ambulatory oncology may represent a critical opportunity to carry out this type of screen, and it may provide a way to take into account certain structural limitations such as the capacity of the specialty palliative care workforce.

In order to achieve greater patient activation toward palliative care, misconceptions must be addressed. Effective patient-provider communication is also central to timely, targeted integration of palliative care, and patients must be empowered participants in this communication. Finally, assessments associated with ambulatory oncology may be beneficial for guiding patients to palliative care.

# Elevating the Research and Treatment Needs of Latino Children, Adolescents, and Young Adult Survivors

*This breakout session occurred at 3:30 p.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Increasing Diversity in Pediatric Cancer Clinical Trials

Dr. Paula Aristizabal is Associate Professor of Pediatrics in the Division of Pediatric Hematology and Oncology, Medical Director of the International Outreach Program, and Quality Improvement Lead at the University of California San Diego and Rady Children's Hospital.

### Disparities in pediatric cancer

Dr. Aristizabal's presentation covered the demographic shift in the US, disparities in pediatric cancer, inequities in clinical trial participation in pediatric cancer research, barriers to clinical trial participation in Latinos, and strategies to improve recruitment of Latinos to clinical trials. The Latino population will likely become the most populous demographic in the US in the next few decades. Texas and California have the largest Latino populations, with San Antonio in particular being 65.8% Latino. Latinos are already California's largest ethnic group, and are projected to comprise 43% of the population by 2030. Clearly, it is imperative to provide the best care possible to this growing population.

Although childhood cancer is the leading cause of death by disease past infancy in the US, with 17,000 children younger than 21 years diagnosed annually, survival has improved dramatically, and is now greater than 80%. Because of unequal access to services and poorer health outcomes, however, disparities in overall survival exist. Latino children have higher incidence of certain cancers, for example lymphoma and leukemia, and poorer survival rates than non-Hispanic White children (74% vs. 81%, $p<0.001$).

### Phases of disparities research

In Dr. Aristizabal's view there are three phases of disparities research. The first phase is "Detecting," meaning defining and measuring cancer disparities such as ethnic disparities in acute lymphoblastic leukemia (ALL) survival, racial disparities in acute myeloid leukemia (AML) survival, and minority underrepresentation in clinical trials. The second phase is "Understanding," or identifying the mechanisms of cancer disparities such as the presence of high-risk biologic features, decreased access to stem cell transplantation, and adverse social determinants of health (e.g., limited health literacy, poverty, and language barriers). The third phase is "Reducing," meaning the development and evaluation of interventions such as dose adjustments for genetic polymorphisms, interventions to improve treatment adherence, interventions to improve participation in clinical trials, and interventions to address poverty.

Some of Dr. Aristizabal's work in the "Understanding" phase of disparities research involves understanding the role of social determinants of health in influencing Latino participation in clinical trials. Minorities are generally under-represented in research, with Latino participants constituting only 1-7% of overall participation. This disparity is even worse in adult cancer clinical trials, with Latino individuals making up only 0.4%-2.2% of overall participation. In fact, only 2% of approximately 10,000 National Cancer Institute (NCI) clinical trials have representative minority participants. This means that cancer outcomes data are largely based on data from non-Hispanic White participants, and there is incomplete information to adequately assess treatment benefits for minorities.

This trend is also present in pediatric cancer clinical trials, with 53% of Latino parents declining participation compared to 20% of non-Hispanic White parents. Dr. Aristizabal's work focused on the role of health literacy, culture, and language in this discrepancy. Beginning with the informed consent process, barriers exist. First, there are no mandates to ensure comprehension, and informed consent forms are complex and difficult to understand. This leaves parents with an incomplete understanding of risks, procedures, randomization, alternative treatments, and the voluntary nature of trial participation. Furthermore, pediatric cancer often requires urgent treatment, leaving little time for decision-making.

### COMPRENDO

Based on this limited health literacy among Latino families, Dr. Aristizabal and colleagues developed COMPRENDO (ChildhOod Malignancy Peer REsearch NavigatiOn), a peer-navigation intervention to improve research literacy and diversity in pediatric cancer clinical trials. In the program, peer-navigators provide in-hospital support, telephone support, and in-home support. The goals of the program are to improve parents' informed consent experience and comprehension of informed consent for cancer treatment, to explain to parents terms and concepts to be discussed by the oncologist during the treatment conference, to introduce to parents concepts of clinical trials, and to facilitate and empower shared decision-making. In fact, this intervention showed increased comprehension of therapeutic trials, particularly in Latino parents and Spanish-speaking parents.

In closing, Dr. Aristizabal shared strategies to increase clinical trial enrollment of Latino individuals. First, not only should the demographics of patients enrolled in clinical trials be comparable to the US population, but approaches to improve enrollment must also be tailored to specific settings. Structural barriers for Latino participation should be considered during study design and informed consent design. Provider-level training focused on patient-provider communication is also important, with linguistically appropriate tools and culturally-aware staff. Finally, key factors at the patient-level include building trust; education and awareness of clinical trials; culture, language, and health literacy-focused interventions; and initiatives to address socio-economic barriers.

## Treatment-Related Toxicity and Pediatric Cancer

Dr. Allison Grimes is Associate Professor of Pediatrics and Director of the Adolescent and Young Adult Cancer Program at the University of Texas Health San Antonio Mays Cancer Center and the Greehey Children's Cancer Research Institute.

### Disparities in pediatric cancer

The central objective of Dr. Grimes's presentation was to recognize disparities specific to Latino children, related to short- and long-term toxicities of cancer therapy. Although pediatric cancer survival in the US now exceeds 80%, survival disparities exist for Latino and Black children, children with low socioeconomic status, and children in underserved areas. Latino children also have higher incidence of several cancers, including leukemia and lymphoma, and have lower 5-year overall survival than non-Hispanic White children (74% vs. 81%). Furthermore, Latino children have more frequent and more severe treatment-related toxicities with several common key drugs utilized in pediatric cancer regimens.

Survival improvements are largely driven by multicenter clinical trials by national and international cooperative groups (e.g., Children's Oncology Group) to improve risk stratification, treatment intensity, and supportive care reducing toxicity. Treatment-related toxicities contribute to significant morbidity, decreased quality of life, and mortality in some. Accurate measurement and reporting of toxicities are critical to understanding the scope of the problem but are routinely under-captured and data is not always linked to race/ethnicity. High-quality, large, multicenter trials are needed to determine if certain approaches can mitigate risk. However, there are obstacles to the development of supportive care trials, including funding and limited participant access.

Late effects and toxicities experienced by pediatric cancer patients may be categorized by organ system. The brain, for example, may experience neurocognitive deficits in association with the use of methotrexate. Alternatively, toxicities may be organized by cancer type, with Ewing sarcoma patients often experiencing cardiomyopathy associated with the use of anthracyclines. A significantly higher number of Latino patients with Ewing sarcoma (82%) experience grade 3/4 toxicity compared to non-Hispanic White patients (56%).

Latino children with acute lymphoblastic leukemia (ALL) experience increased toxicities associated with several common treatments. Latino patients undergoing CAR-T cell therapy, for example, experience more severe cytokine release syndrome compared with non-Hispanic White patients, even adjusting for disease burden and age. Hispanic ethnicity was also found to be associated with an increased risk for creatinine elevation associated with high-dose methotrexate use. In fact, Latino children experienced a nearly 6-fold increase in neurotoxicity odds with serum creatinine elevation ≥50% compared with creatinine elevation <25%. Non-White minorities experience more frequent and more severe hyperglycemia and are more likely to require insulin in association with corticosteroids, mercaptopurine, and asparaginase. Finally, Hispanic ethnicity was identified as a strong predictor of hepatotoxicity associated with asparaginase.

Strategies for reducing toxicity in pediatric cancer patients can include the following approaches: therapy reduction, including reduction of exposure duration, cumulative dosing caps, and risk-adapted therapy plans; the use of less toxic drugs including immunotherapy and CAR-T; the use of pharmacogenomics to drive drug dosing decisions; and increasing the number of supportive care trials.

### An example of a supportive care intervention

It is imperative to design supportive care interventions that target treatment toxicities in pediatric cancer. In light of this need, Dr. Grimes and colleagues have recently undertaken a randomized controlled trial studying the impact of continuous glucose monitoring (CGM) on glycemic control in pediatric, adolescent and young adult (PAYA) ALL patients. Treatment-related hyperglycemia (TRH) associated with corticosteroids and asparaginase affects up to 1/3 of ALL youth, a disproportionate amount of which are Black and Latino. TRH is associated with increased bacterial and fungal infections and diminished survival in ALL patients. However, no standardized approach exists for detecting, monitoring, or managing TRH in this population.

The primary objective of the trial is to determine whether use of unblinded CGM, over standard of care, improves glycemic control as measured by glucose percent time in range (TIR, 70-180 mg/dL), among PAYA patients (age 10-39 years) with newly diagnosed ALL during the initial six weeks of therapy. Dr. Grimes and colleagues hypothesize that access to continuous, real-time glucose measurements obtained via wearable CGM devices will lead to improved glycemic control, as measured by increased TIR, over standard of care. Such practical, supportive care interventions could have great influence in eliminating disparities in the treatment-related toxicity experienced by Latino pediatric cancer patients.

## Improving Cancer Survivorship Care for Latino AYA Survivors

Dr. Jacqueline Casillas is a Professor in the Department of Pediatrics at the David Geffen School of Medicine at the University of California Los Angeles (UCLA), Director of the Pediatric, Adolescent and Young Adult (AYA) Survivorship Program at UCLA, and Medical Director of the Jonathan Jaques Children's Cancer Institute at Miller's Women and Children's Hospital.

### Adolescent and young adult survivors

Dr. Casillas's presentation focused on three main topics: the epidemiology of AYA survivorship, the cost of cure and late effects, and improving care for AYA survivors. In 2020 there were 89,500 new cancer cases in AYA patients, defined as individuals between 15 and 39 years. Although the overall 5-year survival rate in this demographic is 83-86%, survival is lower for racial/ethnic minorities. Currently, there are approximately 675,000 AYA survivors overall.

Cancer is the leading cause of death in the Latino population, accounting for 20% of overall deaths. Although there is limited data for Latino AYAs, cancer mortality rates for patients aged 15-19 declined from 2010 to 2019 by 2% per year. Survival disparities exist for the most common types of cancer for adolescents. Latino patients with leukemia, for example, have survival rates of 71% compared with 82% for non-Hispanic White patients. For Latino adolescents, the most common cancer types are brain, leukemia, lymphoma and germ cell tumors.

### Late effects

Cancer survival comes with the risk of late effects, defined as any chronic or late occurring outcome, physical or psychosocial, that persists or develops beyond 5 years from the diagnosis of cancer. For AYA cancer survivors, late effects are an emerging area of research since this is an understudied population. AYA clinical trials tend to have lower enrollment compared with well-established childhood cancer survivorship studies or survivorship studies done in older adults.

Unique risks exist for AYA survivors, including increased risk of secondary cancers, increased risk of chronic comorbidities, and increased risk of mortality as survivors. AYAs have a higher excess risk for secondary malignant neoplasms than either children or older adults. The cumulative incidence for developing a secondary neoplasm continues to increase over time for AYA survivors is 15 years, highlighting the need for long-term survivorship care. Increased risk of chronic comorbidities are also present, with 40% of AYA survivors experiencing multiple comorbidities at 10 years after index date, compared with 20% of AYAs without cancer. The most common comorbidities were dyslipidemia, hypertension, thyroid disorders, and severe depression or anxiety.

### Clinical trial participation

There is a dearth of data for Latino AYA survivors, partially due to Latino underrepresentation in cancer clinical trials. Factors that contribute to this underrepresentation include a lack of awareness of clinical trials, fear of toxicities and mistrust, transportation issues, a lack of access to academic centers or specialized cancer centers, high rates of uninsured or underinsured, language and communication barriers, the complexity of clinical trial design (particularly for low literacy patients and families), and the unconscious bias of providers.

Given the increased risk for morbidity and mortality in AYA survivors, survivorship care must include several considerations. First, cancer prevention and health promotion counseling must be provided for risk reduction, including counseling on tobacco exposure and cessation, alcohol use, diet, exercise, and obesity prevention. Next, screening must be prioritized for early detection of late effects including medical and psychosocial outcomes. Hereditary genetic predispositions and appropriate genetic counseling should also be considered. Finally, assessment of cultural beliefs, environment, and inclusion of Latinos in research should be prioritized in order to develop interventions to achieve health equity in cancer survivorship care.

### Interventions

Because of the developmental stage of AYA survivors, cancer diagnosis may disrupt their independence from their parents and healthy peers. These survivors may wish to identify with a peer support group for others diagnosed and treated for cancer, which could optimize health outcomes. Survivorship care may be seen as intrusive and they may want to re-immerse themselves with healthy peers. Furthermore, since this population is very mobile, attendance at follow-up visits may be sporadic. Two interventions developed by Dr. Casillas and colleagues included a photonovela, used for educational intervention, and a text messaging system, used to remind and educate AYA survivors on their risk for late effects and the importance of survivorship care planning and healthy lifestyles. Such interventions can help clinicians interact with AYA survivors more effectively, and help survivors to be engaged in seeking survivorship care.

Minorities are less likely than non-Hispanic White individuals to be confident in a survivorship care plan, which can prepare survivors to be more self-assured in being their own health advocates. Latinos in particular can benefit from inclusion of the nuclear family in survivorship care discussions. However, a cancer stigma associated with survivorship discussions exists in the Latino community, resulting in continued emotional distress related to discussions regarding cancer diagnosis and treatment. Interventions targeting de-stigmatization of survivorship care in AYA-appropriate ways can make a difference in Latino cancer outcomes.

# Addressing Latino Cancer Health Equity by Exploring Social Determinants of Health

*This breakout session occurred at 3:30 p.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Designing Food Pantries to Improve Food Security Among Cancer Survivors

Dr. Sandi Pruitt is Associate Professor and Associate Director of Community Outreach, Engagement, and Equity in the Harold C. Simmons Comprehensive Cancer Center at the University of Texas Southwestern Medical Center. She also serves as Vice Chair of the Board of Directors for Crossroads Community Services.

### Food security and cancer

Dr. Sandi Pruitt's presentation discussed food security and cancer, best practices and solutions, and a Dallas pantry redesign. The gold standard for measuring food security is the validated US Food and Drug Administration (FDA) survey, which is offered in 6, 10, and 18 question options. In the survey, "high food security" describes households having no problems, or anxiety about, consistently accessing adequate food. "Marginal food security" describes households having problems at times, or anxiety about, accessing adequate food, but the quality, variety, and quantity of their food intake are not substantially reduced. "Low food security" describes households with reduced quality, variety, and desirability of their diets, but the quantity of food intake and normal eating patterns are not substantially disrupted. "Very low food security" means that at times during the year, eating patterns of one or more household members are disrupted and food intake is reduced because the household lacks money and other resources for food. In clinical practice, since a lengthy survey is not practical, a 2 question screening tool called Hunger Vital Sign may be used.

In 2021, 10% of US individuals were food insecure, a rate which is much higher when considering children alone. In Texas, 13.7% of individuals were food insecure in 2021. Across the cancer continuum, food insecurity reduces adherence to therapy, compromises cognitive capacity, lowers access to resources, and is linked to worse overall physical health and mental health, including stress, anxiety, and depression. Malnutrition is common among cancer patients, ranging from 40-80%, and tumors and their associated pain, depression, and stress can impact appetite. Malnutrition can also increase the side effects and adverse reactions of cancer treatment and can lead to extended hospital stays.

In the US, from April 2020 through August 2021, Latino adults had 17.3% food insecurity, second only to non-Hispanic Black adults at 18.9%. Between 1999 and 2018, US born Latino individuals had 21% food insecurity, while foreign-born Latino individuals had 32% food insecurity. Latinos speaking predominantly English had 19% food insecurity, a number that rose to 26% among those who spoke English and Spanish equally, and 34% among those speaking predominantly Spanish.

### Best practices and solutions

Federal food programs for mixed age groups include grocery programs such as food bank-operated pantry programs, ad hoc food pantries, home-delivered groceries, mobile markets and pantries, school or other pantries, and community gardens. Meal programs are also important, such as food bank-operated meal programs, community kitchens, group homes and transitional housing programs, rehab and residential programs, and soup kitchens. Finally, food-related benefits programs such as Supplemental Nutrition Assistance (SNAP) (in which 40 million Americans are enrolled) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) are also helpful.

Food banks collect surplus food from government commodities, restaurants, farms, markets, consumers, and grocery retailers. They then typically deliver the food to community service organizations, who in turn distribute the food to those in need. Through the COVID-19 pandemic, food banks and other services increased activity drastically, resulting in no increase in food insecurity from 2019 to 2020. However, when this increase in services was rolled back in 2023, food insecurity increased; in Texas, those without enough to eat over a 1-week period increased by 60% between 2021 and 2023. This shows the utility of food banks and other services in minimizing food insecurity.

Building food security in cancer care involves 5 A’s: awareness through empathetic, non-stigmatizing screenings; adjustment of clinical workflows to accommodate assessment and mitigation; assistance of cancer patients through useful guidance and resources; alignment by investing in partnerships with local organizations; and advocacy for policies to prevent food insecurity.

### Dallas pantry redesign

Through partnerships with organizations such as Crossroads Community Services, Dr. Pruitt and colleagues have designed an innovative food pantry that emphasizes food equity, meaning client choice is prioritized and a nutrition-based food selection system is utilized. An algorithm is used to match the amount of food to the need, and there are no restrictions on food types. At each visit, this food pantry provides enough food for 21 meals per household member; enough for everyone to have enough food for one full week of food. On average, this pantry provides 100 pounds of groceries per family of four and families can attend the pantry once per month. The redesigned food pantry has also moved away from a hub model to a partnership model within the community, resulting in increased pantry visit frequency and therefore food security.

Changing pantry operations can save time, resources, and increase impact, overcoming the obstacles and stigma associated with food insecurity. This has enormous potential to improve food security and nutrition of cancer survivors and caregivers to transform health. When combined with best practices and common-sense policy, these interventions can greatly improve the food insecurity experienced by many Latino individuals. However, community engagement and true partnership is needed to achieve these goals.

## How to Help Latina Mothers Who are Diagnosed with Cancer

Dr. Rebecca Palacios is Professor in the College of Health Education and Social Transformation in the Department of Public Health Sciences at New Mexico State University.

### Cancer in Latina mothers

Dr. Palacios' presentation focused on discovering and addressing social determinants of health experienced by diagnosed Latina mothers in the Paso del Norte border region, which includes bordering areas of Texas, New Mexico, and Mexico. Every year, approximately 144,154 Latino individuals are diagnosed with cancer, 18.3% of which are parents of minor children. Of these recently diagnosed parents, 78.9% are female, meaning that over 20,000 Latina mothers are diagnosed with cancer each year.

All cancer site incidence is rising in Latina women under the age of 50, both in the border states and nationwide. US incidence is 110.3 per 100,000, with Texas slightly higher at 111.5 per 100,000, and New Mexico even higher at 115.2 per 100,000. Cancer incidence in young Latinas is even higher in the Paso del Norte border region, with El Paso County, TX incidence at 126.6 per 100,000, and Doña Ana County, NM incidence at 122.3 per 100,000.[,]

Although Latina women have much lower incidence of breast cancer than non-Hispanic White (NHW) women nationwide, this trend is non-existent in El Paso County, or in New Mexico at large. In Doña Ana County, NM specifically, the trend is reversed, with Latina women showing significantly higher incidence of breast cancer. Furthermore, Latina women tend to be diagnosed at a younger age (median 55 years vs 59 years for NHW women), with 35% of Latina women diagnosed before the age of 50 compared to 24% of NHW women.

Although cancer screening guidelines have been adjusted so that women over 40 are now eligible for breast cancer screening, 12% of cancer cases in Latina women present before age 40. Latina women also have a higher incidence of triple-negative breast cancers which have fewer treatment options and a poorer prognosis compared to other subtypes. Latina underrepresentation in clinical trials means that most health-related research and practice is based on NHW, urban, middle-class, American "norms".

Solutions for young Latina mothers diagnosed with cancer must begin with an increase in clinical research, including intentional recruitment in Latino-dense regions and public health and clinical collaboration leading to Spanish consent forms and culturally adapted recruitment and study materials. Emphasis must also be placed on increasing young Latinas' awareness of their risk for earlier cancer presentation and training them on breast self-exam guidelines. Clinician awareness of early cancer presentation in young Latinas, including training on screening for risk factors, is also vital. Finally, young Latinas need training to communicate with their doctors so they can successfully advocate for their health.

### Social determinants of health along the border

Dr. Palacios and colleagues studied the social determinants of health that impact the Paso del Norte border region, including Las Cruces, NM, El Paso, TX, and Juárez, Mexico. This is a medically underserved region with no comprehensive cancer centers, limited cancer prevention and support groups, and limited cancer survivor education and behavioral interventions. Socio-economic determinants of health for young Latina women in this area were stark. Compared with other young Latina women nationwide, those in the border counties had higher poverty rates, higher chances of leading a household as a single provider, higher rates of uninsured, and lower high school graduation rates.

Low socio-economic status is associated with less access to insurance and time off from work, greater cancer-related financial toxicity, lower access to high-quality care, and higher risk factors for developing or dying from cancer.[,] Limited English proficiency and undocumented status are also associated with significant barriers to care.[,] Comprehensive centers are needed in underserved areas to combat these barriers. Incentives for cancer specialists/researchers to serve in these areas, expanding the number of Latino or Spanish speaking clinicians, and increasing education/support/services for Latina mothers diagnosed with cancer may help mitigate these barriers. Policy changes are also key to helping young Latina mothers.

### Qualitative research and interventions

Qualitative research performed by Dr. Palacios and colleagues has led to a deeper understanding of personal struggles experienced by Latina mothers with cancer. Feelings of loneliness, guilt, difficulty at home, difficulty communicating with their children, needing support during treatment, and feeling like the treatment was worse than the disease were common themes.[,] The Conexiones program is a culturally-tailored, evidence-based cancer parenting intervention designed for child-rearing Latina mothers diagnosed with cancer. Program interventions include 5 cancer education sessions designed to reduce maternal depressed mood and anxiety, improve parenting quality, skills, and self-efficacy, and to improve children's behavioral/emotional adjustment to their mother's cancer. The cultural adaptation was geared toward improved comprehension and cultural relevance, and added protocols for domestic violence, self-harm and suicide, and socio-economic status burdens.

Lessons learned through the Conexiones program and other research indicate the need for a multifaceted approach to helping young Latina mothers diagnosed with cancer. Medical assistance is needed for symptom management, including preparing Latinas on what to expect and strategies for managing extreme side effects; there is also a need for training and recruiting pain management and behavioral health specialists to underserved regions. Culturally adapted cancer education programs can help address disparities in social determinants of health. Finally, health equity-focused research strategies such as community-based participatory research, clinical trials exclusive to young Latinas, and new research strategies and instrumentation may help progress the research efforts with young Latina mothers diagnosed with cancer.

## Rapid Fire Session

*This breakout session occurred at 5:15 p.m., Wednesday, Feb. 21, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

### Residence in a Latino Enclave and Clinical Outcomes in Texas Children with Acute Lymphoblastic Leukemia

Dr. Jeremy Schraw is an Assistant Professor in the Division of Hematology-Oncology, Department of Pediatrics, at Baylor College of Medicine.

Dr. Schraw began by pointing out the higher incidence of acute lymphoblastic leukemia (ALL) among Latino children, and the poorer overall survival (OS) following diagnosis. Social determinants of health likely contribute to these disparities. In fact, children living in Latino enclaves, defined as neighborhoods with a high proportion of Latino residents, recent immigrants, and linguistically isolated households, have poorer OS after diagnosis of ALL.

Dr. Schraw and colleagues set out to determine whether residence in an enclave is associated with certain outcomes after adjusting for clinical and demographic factors. The primary outcomes were clinical trials participation, minimal residual disease (MRD) at the end of induction chemotherapy, and OS. According to adjusted analysis, patients living in Latino enclaves were found to be less likely to be enrolled in a clinical trial than patients living in other neighborhoods (46.2% vs 65.4%, OR 0.55, 95%CI 0.11-2.82), more likely to be MRD positive at end-induction (24.1% vs 20.7%, OR 1.11, 95%CI 1.04-1.20), and more likely to die from their disease (1.4% vs 0.6%, OR 1.20, 95%CI 1.12-1.28).

These results demonstrate the association between neighborhood context and adverse outcomes across treatment, suggesting that early clinical events may mediate ethnic and socioeconomic disparities in ALL outcomes. Furthermore, the study highlights the importance of neighborhood social context for pediatric cancer and for health disparities in Hispanic or Latino people.

### Unraveling Genomic Ancestry in a Hispanic/Latino Colorectal Cancer Cohort and Exploring Spatial Transcriptomics to Study the Tumor Microenvironment

Dr. Enrique I. Velazquez-Villarreal is an assistant professor in the department of integrative translational sciences at City of Hope.

Dr. Velazquez-Villarreal described a study performed with colleagues at City of Hope, analyzing clinical and genomic data from 82 Hispanic/Latino individuals with primary colorectal tumors in order to assess global and local genomic ancestry. The data was collected using the Oncology Research Information Exchange

Network, and the genomic ancestry analyses estimated the proportion of Latino genetic makeup from five superpopulations: Admixed American, European, South Asian, East Asian, and African.

Global genomic ancestry analysis unveiled a significant population admixture, with high proportions of Admixed American (4.9 - 70%) and European (2 – 48%) components, followed by South Asian (4.5 – 26.1%), East Asian (0 – 24.5%), and African (0 – 7.4%) components. Patients with an Admixed American component were found to have a higher risk of early onset colorectal cancer. Each chromosome was also analyzed locally to identify genes of interest and determine ancestry.

In addition to this primary analysis, a secondary investigation involved two spatial transcriptomic colorectal cancer samples sourced from the 10xGenomics database in addition to the patient samples collected. The analysis of these samples involved quantifying gene activity relative to specific tumor locations. This approach represents a new technology for assessing how components of colorectal cancer are interacting in the tumor microenvironment within Latino patients.

## Padres y Trabajadores de la Salud Unidos en la Prevención Del Cáncer: A Multi-Tiered Intervention Approach to Increasing HPV Vaccination

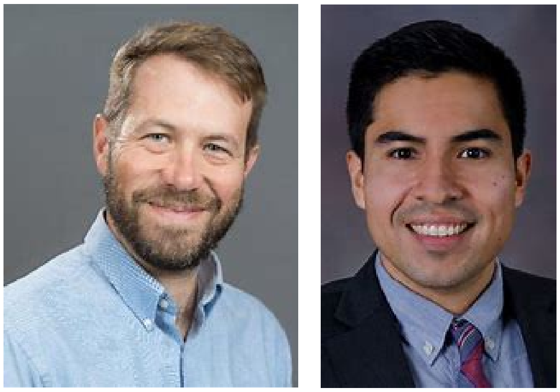
Dr. Jacob Martinez is an Assistant Professor in the college of Nursing at the University of Texas at El Paso.

Dr. Martinez described the process of developing a multi-tiered health literacy intervention with the goal of increasing human papillomavirus (HPV) vaccination among children aged 9-17 years in 3 underserved communities in El Paso County, TX. Interventions involved educating professionals and the public by providing HPV vaccination messaging, and facilitating access through community-based clinical services. Intermediate goals included reducing the number of missed clinical opportunities for recommendation and administration, increasing parental acceptance of the vaccination, and maximizing equitable access to vaccination services. The long-term goal was decreased rates of morbidity and mortality due to HPV-associated cancers.

Within the first 10 months of this initiative, several steps have been successfully taken. First, a bilingual comic has been developed to help with HPV vaccination education. A partnership has also been established with the American Cancer Society to train community health workers, and parent education sessions are being provided for cancer prevention education. Finally, partnerships with federally qualified health centers are in place to analyze missed opportunities and to strategize effective approaches to increased vaccination.

Barriers to this work are multitudinous and include vaccine shortages, accessibility of services, affordability and availability, provider missed opportunities, and difficulties in tracking vaccine administration. Factors that help mitigate these barriers, however, include interventions by community health workers, which can strengthen patient navigation and advocacy skills; transportation to and from federally qualified health centers; open dialogue with federally qualified health centers; and the identification of other vaccine providers for HPV and other vaccines.

## Building a Primary Care Research Agenda for Latino Populations in the Setting of the Latino Paradox: A Report from the 2023 Latino Primary Care Summit



Dr. Miguel Marino is an Associate Professor of Biostatistics in the Department of Family Medicine at Oregon Health and Science University. Dr. John Heintzman is an Associate Professor of Family Medicine at Oregon Health and Science University, and an Affiliate Investigator at OCHIN, Inc. Drs. Marino and Heintzman are also Co-Directors of the Primary Care Research Equity In Latinos (PRIMER) Center.

Drs. Marino and Heintzman discussed the inaugural Latino Primary Care Summit, held in 2023. The main topic of discussion for the summit was the Latino Paradox, an epidemiologic phenomenon which describes the lower all-cause mortality rates among US-based Latinos versus their socioeconomic comparators. Discussion and recommendations were organized into 6 themes.

The first theme involved Latino paradox considerations, limitations, and implications, and included recommendations to regularly update a working definition of the Latino paradox. The need for research on how conceptions about the Latino paradox are used or misused by clinicians in health care systems was also noted.

The second theme covered data issues. Latino data is often disaggregated due to inconsistent definitions and questionnaires. Funders, researchers, and primary care clinics need to work together to address this issue while partnering with Latino communities.

The third theme focused on bridging the clinic and community. Research is needed to better understand how to support, utilize, and develop community health workers, and quantify their impact on Latino health.

The fourth theme, primary care challenges, emphasized the need for practice-based evidence on effective care to Latino communities, including payment reform and overall care design in primary care settings. New and ongoing research should also provide insights as to how the pandemic has impacted the Latino Paradox, primary care utilization, and their intersection.

Social needs were the focus of the fifth theme. Participants discussed the need to study the acceptability of social screening approaches in primary care workflows to understand implementation among Latinos. Importantly, these screening approaches should be culturally informed.

The final theme for the summit was workforce and academic representation, and inequities and innovation. When evaluating early-career proposals, funders should highly value innovative and exploratory research approaches that address the Latino community, in order to robustly address long-standing Latino health inequities and expand the Latino research workforce.

## Clinical and Genomic Characteristics of Early-Stage Breast Cancer Tumors of Latin American Patients in FLEX Study

Dr. Marcela Mazo Canola is an assistant professor within the Division of Hematology-Oncology at The University of Texas Health Science Center San Antonio and a breast medical oncologist at Mays Cancer Center, home to UT Health San Antonio MD Anderson Cancer Center.

Dr. Canola began by explaining that the clinical and genomic characteristics of breast cancer can vary significantly across different ethnicities. In light of this, the FLEX study was used by Dr. Canola and colleagues to further understand the characteristics of early breast cancers in Latin American patients.

The first finding of note was the number of participants in the different cohorts, with 9738 non-Hispanic White participants and only 386 Latina participants. The Latina cohort was also found to be younger (mean age 55.58 vs 61.10), have more T3 and T4 tumors, and have a higher grade of disease. Furthermore, this group had higher rates of obesity and type 2 diabetes, and had more aggressive disease, with a statistically significantly higher percentage of MammaPrint (MP) High risk 2 disease. Although the Latina cohort showed less of the luminal A molecular subtype, a statistically significantly higher number of cases of basal type breast cancer was observed. A difference was also noted in the percentage of women receiving chemotherapy in the neoadjuvant setting, with 51.2% of the Latina group receiving chemotherapy compared with only 27.7% of the non-Hispanic White group.

These clinical characteristics, together with MammaPrint and BluePrint, reflect the high-risk features of breast tumors in Latin American patients. Along with the higher rates of chemotherapy treatment, these findings highlight the importance of real-world evidence cohorts like FLEX, and the value of increased clinical trial enrollment in the Latin American population.

## Adapting NCI's Clinical Trials System to a Changed Clinical Research Environment

Dr. James H. Doroshow is Deputy Director for Clinical and Translational Research at the National Cancer Institute (NCI).

*This plenary session occurred at 8:30 am., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

### COVID's impact on cancer clinical trials

Dr. Doroshow's presentation began by discussing the initial and continuing effects of the pandemic environment on cancer clinical trials. From the start of the pandemic, several aspects of clinical trials were altered, including informed consent and in-person study activities. One major ongoing issue is the critical shortage of research nurses, clinical research associates, and research office regulatory staff, as well as essential health care workers and institutional central research service workers. These shortages have diminished trial availability and accrual, including for underserved populations, and led to substantive delays in results reporting. Monthly enrollment in treatment trials at National Cancer Institute (NCI)- designated cancer centers also decreased drastically in early 2020. As a matter of fact, annual enrollment is still down about 25% compared with 2019 enrollment.

In response to this decrease in enrollment, the NCI launched the Cancer Center Clinical Trials Workforce Survey to assess the ongoing impact of the COVID-19 pandemic on the capacity of Cancer Centers to conduct treatment trials. The survey was administered by the Science Technology Policy Institute (STPI) and had a response rate of 100% of clinical cancer centers. Results of the survey showed that one major impact on accrual was limited research staff capacity, preventing openings and forcing accrual holds. This loss of personnel was largely associated with research staff leaving for the higher pay offered by pharma companies and clinical research organizations (CROs), who offered higher compensation to insulate themselves from pandemic-driven staff shortages.

### NCI's vision for clinical trials

In response to these issues, the NCI's Clinical Trials and Translational Research Advisory Committee (CTAC) developed a 2030 Vision for Clinical Trials to re-assess the strategic vision for the clinical trials system for 2030 and beyond. The CTAC developed 15 recommendations and 3 operational initiatives to develop more flexible, faster, simpler, less expensive, and more high-impact clinical trials that seamlessly integrate with clinical practice. The vision, therefore, is focused on streamlining processes for trial design and execution, focusing on essential endpoints, decreasing regulatory hurdles, broadening trial access, and increasing the efficiency of data collection.

One specific recommendation involved limiting data elements collected in clinical trials. Limiting clinical trial data collection in late phase trials to essential data elements allows for greater efficiency and lower cost. Low-value data categories were identified: low-grade adverse events and attribution start/stop times, laboratory data that is beyond the standard of care or unrelated to study endpoints or safety monitoring, unused components of panels including unnecessary repetition of full panels, imaging that is beyond the standard of care, concomitant medications that are not relevant to the protocol, start dates for concomitant medications not linked to protocol eligibility or safety, start dates for histories not linked to protocol eligibility or safety, and patient position and resting status for vital signs. Eliminating these data collection elements is expected to reduce operational burden and provide important insights that will inform development of data collection standards for other types of trials.

A second recommendation concerned using electronic health records (EHRs) to support clinical trials. The CTAC recommended engaging vendors to create mechanisms for automatically integrating study-specific documents into local implementations of their products. Furthermore, vendors should be challenged to resolve the logistical and data quality challenges of extracting clinical trial data from electronic health records.

Several other recommendations are focused on addressing critical clinical trial workforce issues: streamlining and standardizing trial activation processes, reducing the volume of trials staff are responsible for, increasing flexibility for remote work, improving alignment of institution and cancer center hiring processes related to staff recruitment and retention, and considering a new NCI training grant program supporting the development of careers in clinical trials at NCI-designated Cancer Centers.

### The Virtual Clinical Trials Office

Dr. Doroshow’s presentation ended with a discussion of a Virtual Clinical Trials Office (VCTO) pilot study to expand clinical trials to underserved patients. In this study, research nurses, CRAs, and regulatory affairs personnel are organized through the NCI-Frederick National Lab Clinical Research Directorate. Initial services under consideration include the following: eligibility screening and study coordination to promote trial entry of underserved patients; assistance with informed consent, enrollment, protocol queries, and ‘help desk’ functions; data entry/abstraction from EHR; coordination of study visits, procedures, and participant reminders; regulatory support; and adverse event reporting.

If the pilot proves successful, the VCTO could extend the reach of clinical trials to many underserved populations by providing these services directly to physicians’ offices. This type of program, in coordination with other recommendations put forth by the NCI’s 2030 Vision for Clinical Trials, could accomplish a great deal in the simplification, and therefore effectiveness, of clinical trials. In this way, decreases in clinical trial enrollment and staff shortages initiated by the pandemic may be overcome.

# Promoting Structural and Institutional Change to Reduce Poverty and Cancer

Dr. Shobha Srinivasan is Senior Advisor for Health Disparities in the Office of the Director, Division of Cancer Control and Population Sciences (DCCPS), at the National Cancer Institute (NCI).

*This plenary session occurred at 9:10 am., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

**Poverty in America**

Dr. Srinivasan began by discussing poverty and how it connects to health. Despite advances in cancer prevention, diagnosis, treatment, and survival, disparities in cancer outcomes continue to persist with increased mortality among people living in poverty. Disparities are further exacerbated for those living in geographically underserved areas, defined as areas with high and/or persistent poverty.

Information from the US Census Bureau on real median household income by race and Hispanic origin of householder in 2021 shows Asian households to be the highest earners, at $101,400, while Latino households only earn $58,000. Latino individuals also have the second highest rate of medical debt, behind only Black individuals. Again, the Latino poverty rate is slightly less than the Black poverty rate, 17.1% and 19.5% respectively in 2021, while the poverty rate for non-Hispanic White individuals is 8.1%.

When considering the ratio of poverty population to total population, American Indian and Alaska Natives have the worst ratio. This group makes up 1.2% of the total population, but represents 2.6% of the poverty population, a ratio of 2.2. Latino and Black individuals have the second worst ratio, at 1.5, with Latino individuals making up 19.3% of the total population, but 28.4% of the poverty population.

When looking specifically at child poverty, massive gains were made during the pandemic due to the programs and emergency provisions provided. However, much of that gain has been lost with the expiration of these programs. In America, nearly 11 million, or 1 in 7, children are poor.

The housing crisis further contributes to poverty in many ways. Individuals without an address cannot obtain Medicaid, for example. Extremely low-income families across the US need 6.8 million more affordable housing units, and 70% of this group spend more than half of their income on rent. On any given night, over 580,000 people are experiencing homelessness. Only 1 in 4 extremely low income families who need assistance receive it.

Education and poverty are inextricably linked. Those with no high school diploma have a poverty rate of 25.2%, compared with a poverty rate of 4.3% among people with a bachelor's degree or higher. Incarceration is another factor that is intimately tied to poverty. At the end of 2022, 32% of inmates were Black, a group that makes up 13.6% of the overall population, and 23% of inmates were Latino, a group that makes up 19.1% of the overall population. In contrast, 31% of inmates were White; White individuals make up 58.9% of the overall population.

### The Persistent Poverty Initiative

Persistent poverty is defined as an area where 20% or more of the population has been in poverty for the last 30 years. Dr. Srinivasan and colleagues have shown that people living in US counties with persistent poverty are more likely to die from cancer than people living in other counties. This risk is above and beyond the heightened risk seen in areas experiencing current but not persistent poverty.

The Persistent Poverty Initiative (PPI) aims to address structural and institutional factors to alleviate the cumulative effects of poverty on cancer outcomes by building research capacity, fostering cancer prevention research, and partnering with communities to promote the implementation of community-based programs. Awards have been given to five specialized centers who will work with targeted low-income communities in persistent poverty census tracts. Centers will also train a pipeline of early-career investigators to work with underserved communities in conducting multilevel intervention research.

The five specialized centers include the following: the MD Anderson Cancer Center, which is focused on nutritional interventions in elementary schools and physical activity interventions for cancer survivors; the University of Alabama Birmingham, which is focused on individual health-related activities to improve cancer outcomes and diet and exercise interventions for cancer survivors; Stanford University, which is focused on assessing the effect of guaranteed basic income on determinants of cancer outcomes and testing whether the earned income tax credit promotes the uptake of health promoting behaviors; Weill Cornell Medicine, which is focused on school-based cancer education and social justice curriculum and tobacco cessation; and the University of Utah, which is focused on addressing tobacco cessation and addressing obesity prevention and social determinants of health among American Indian rural and frontier communities. These initiatives and others are driving change and promoting health outcomes among populations living in persistent poverty in the US.

# The Importance of Latino Representation for Advancing Population Health

*This plenary session occurred at 9:50 a.m., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Demographics and Public Policy: Implications for Latino Cancer

Dr. Elena V. Rios is President & CEO of the National Hispanic Medical Association (NHMA) and president of NHMA's National Hispanic Health Foundation.

### Inequity in the healthcare system

Dr. Rios's presentation began by focusing on the changing demographics in the US. By 2035, Latino individuals will make up 1 out of every 4 Americans, meaning that the future of the country is intertwined in the Latino experience. The current 63 million Latino individuals in the US make up 19% of the population; however, only 9% of oncologists are Latino, and only 1/3 of those are women. This is important in light of the high incidence of breast and cervical cancer in Latino communities. Furthermore, 20% of Latino physicians are over the age of 64, meaning retirement could make disparities even more pronounced.

Very few medical school faculty and clinical researchers are Latino as well. Only 10% of National Cancer Institute (NCI) trials are run by Latino researchers, and that number is only 4% for the US Food and Drug Administration (FDA). Furthermore, only 9% of cancer center directors and 4.5% of deputy directors are Latino, meaning fewer role models for the next generation.

Latino cancer patients face many barriers to care, with less insurance coverage, less access to screening, higher prevalence of uncontrolled cancer, and more chronic illness. Latino cancer survivors report lower quality of life and unmet supportive care needs. The language barrier also affects every part of the cancer care continuum. Policy changes are required to address community concerns such as education, poverty, food, housing, and transportation. Because of inherent bias in the healthcare system, patient advocates are needed.

### Current policies

Public policy should focus on increasing trust in medical research and medical institutions, as well as increasing patient interest and confidence in effective new treatments. In terms of trial participation, paying community organizations to get involved could be effective. Generating biomedical knowledge is also important. Funding for engaging underrepresented populations in STEM fields is already available, from the US Department of Health and Human Services (HHS), the NCI, the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality at the FDA, the National Science Foundation, the Department of Education, the Department of Energy, and the Department of Commerce. The Advanced Research Projects Agency for Health (ARPA-H), of which the National Hispanic Health Foundation (NHHF) is a member, makes pivotal investments in breakthrough technologies and broadly applicable platforms, capabilities, resources, and solutions with the potential to transform important areas of medicine and health that cannot readily be accomplished through traditional research or commercial activity. The HHS under the Biden administration has also enforced a new equity health plan, focusing on health equity across all agencies.

### The National Hispanic Health Foundation

The National Hispanic Medical Association (NHMA) is a nonprofit started in 1994 with the mission of empowering Latino physicians and Latino-serving physicians to improve the health of Latinos. The NHHF is the 501(c)(3) arm of the NHMA that generates interest in research, initiates educational activities, provides executive leadership development, and organizes networking opportunities. The most important function of the NHMA is the initiation of health communications campaigns, which may address cancer, obesity, diabetes, heart disease, or others. Working with the American Cancer Society (ACS), for example, a congressional briefing is being organized, resources are being developed, networks are being connected, and newsletter campaigns are being initiated.

The NHHF, however, is focused more and more on clinical research, relying on the new partnership with ARPA-H to open the door to more opportunities for Latino participation in research. In the field of advocacy, the NHHF is working with the Congressional Hispanic and Congressional Black Caucuses to enact legislation that would ease barriers to Latino healthcare. In education, the NHHF offers the California Leadership Fellowship and the National Hispanic Professional Student Scholarship.

Finally, the NHHF has also focused on the development of a National Center for Hispanic Health Research, which is developing a repository of about 5,000 Latino physician principal investigators. This center is also involved in hosting clinical research symposia, webinar series, and a career pathway program to mentor medical students. Partners include the HHS, ARPA-H, Johnson and Johnson, Amgen, and Equitable Breakthroughs in Medicine Development (EQBMED). EQBMED is a 2-year pilot project funded by Pharmaceutical Research and Manufacturers of America (PhRMA) and led by Yale School of Medicine, Morehouse School of Medicine, Research Centers in Minority Institutions (RCMI) Coordinating Center located at Morehouse School of Medicine, and Vanderbilt University Medical Center. The project involves 10 clinical sites assessing how patients and providers can be trained to facilitate more diversity within clinical trials.

Policy programs such as the ones mentioned may be instrumental in addressing healthcare disparities in the US. The NHHF is leading the way in this effort, engaging with legislators, interacting with HHS, promoting research initiatives, and providing scholarships for a more equitable future in health research. The development of the National Center for Hispanic Health Research may provide the specificity needed to address disparities specific to the Latino community.

## The All of US Research Program

Dr. Martin Mendoza is Director of Health Equity for the All of Us Research Program at the National Institutes of Health (NIH).

### Representation in clinical trials

The goals of Dr. Mendoza's presentation were to share an overview of the deficiency of representation in clinical trials, review recent efforts to increase clinical trial diversity, and highlight the ways in which the All of Us Research Program is expanding these efforts. The underrepresentation of certain communities in biomedical research is startling. Minority populations make up 38% of the overall population, and that number is expected to reach over 57% by 2045. However, minority enrollment in clinical trials is less than 10%. Latino individuals in particular comprise 18.5% of the US population, but only 3.1% of NIH clinical trial participants nationwide, and 2.7% of FDA novel drug trial participants.

More recently, however, the US Food and Drug Administration (FDA) has taken some small steps forward in this area. In February of 2022 for example, and for the first time ever, an FDA advisory panel recommended against approving the application of an oncology drug because the diversity of the population in the trial did not match that of the US. The trial was conducted exclusively in China, which has a very different demographic than that of the US.

In another step forward, in October 2016, the FDA recommended that "a plan to address inclusion of clinically relevant subpopulations should be submitted [by sponsors] for discussion to the Agency at the earliest phase of development and, for drugs and biologics, no later than the end of the phase 2 meeting." The basis of this recommendation was ultimately written into law in December 2022 by Congress.

**All of Us**

Another step toward equitable representation in clinical research is the All of Us Research Program. The All of Us Research Program is a historic, longitudinal effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, socioeconomics, environment, and biology, the hope is that researchers will one day uncover paths toward delivering precision medicine – or individualized prevention, treatment, and care – for all of us. The All of Us Research Program is the cornerstone of the United States federal government's Precision Medicine Initiative.

There are three pillars of the All of Us mission. The first is nurturing partnerships for decades with at least a million participants who reflect the diversity of the US. The second part is delivering one of the largest, richest biomedical datasets that is broadly available and secure. The third part of the mission is catalyzing an ecosystem of communities, researchers, and funders who make All of Us an indispensable part of health research.

All of Us has a deep focus on community, participant engagement, and researcher engagement and outreach. These goals are accomplished through the following strategies: building relationships, advancing engagement science and application, and engaging to retain.

The All of Us research program is committed to returning value to its participants. As of February 2024, over 254,000 participants have been invited to see their genetic ancestry and trait results, over 171,000 participants have viewed their genetic ancestry results, and over 168,000 have viewed their genetic trait results.

Genomic health-related results are also available, with the program currently looking for genetic variants in 59 genes associated with serious health conditions and analyzing 7 genes that can affect how bodies metabolize medicines. Over 217,000 participants have been invited to view the health results generated. Over 94,000 have viewed hereditary disease risk results, and over

89,000 have viewed pharmacogenomics results. In fact, the All of Us program is now notifying over 5,000 participants per week of the availability of their health results.

The All of Us Research Program is making great strides not only in collecting data from a diverse population, but also in sharing that data and making it available to other researchers. Much information has already been gleaned from this data, including the effects of birthplace on liver cancer rates among Latino individuals, which can provide insights into health disparities and how to solve them. With this wealth of continually growing and diverse health data, many more discoveries are on the horizon.

# Advancements in Data Science and Precision Medicine: Implications for Cancer Prevention, Treatment and Survivorship in Latinos

*This plenary session occurred at 10:50 a.m., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Integrating Clinical and Genomic Data for Tumor Molecular Profiling in Latino Patients with Cancer

Dr. Enrique I. Velazquez-Villarreal is Assistant Professor in the Department of Integrative Translational Sciences at Beckman Research Institute and the City of Hope Comprehensive Cancer Center.

### Multi-omics and colorectal cancer in Latinos

Dr. Velazquez-Villarreal's presentation discussed how multi-omics can be used to understand colorectal cancer disparities in Latino individuals and how global and local ancestry impacts these disparities. He also described clinical and genomic data integration in colorectal cancer disparities and recent technologies used to understand the tumor microenvironment. Multi-omics is a powerful tool in characterizing tumor cells in Latinos, and it works by combining structural genomics (whole exome sequencing, whole genome sequencing), functional genomics (RNA sequencing), epigenomics, and spatial transcriptomics. By integrating this information with clinical data and epidemiological findings, the dream of precision medicine may be realized. However, the amounts of data involved in these analyses may be overwhelming and may require innovative tools such as machine learning and artificial intelligence.

Dr. Velazquez-Villarreal and colleagues have recently used this aggregation of data to try to discover why Latinos have increased rates of early onset colorectal cancer. Global genomic ancestry analysis of 82 Latino individuals with colorectal cancer revealed significant population admixtures, with high proportions of Admixed American (70%) and European (48%) components, followed by South Asian (26.1%), East Asian (24.5%), and African (7.4%) components. This data was integrated with information about each patient's ancestry, age, collection site, tumor content, gender, and more to generate a full multi-omic picture.

Some outliers were observed. One patient with mostly East Asian ancestry self-identified as having Spanish/Hispanic/Latino ethnicity and chose "other" to describe their race. Another patient identified as White racially, with a Cuban ethnicity, but had a largely African ancestry. These outliers underline the importance of multi-omics to provide a full picture of each individual.

The data gathered by Dr. Velazquez-Villarreal and colleagues revealed important patterns in colorectal cancer presentation. For example, patients diagnosed at an earlier age tended to have a higher Admixed American component. Patients with a larger Admixed American component had a higher risk of colorectal cancer compared with patients with higher European, East Asian, African, and South Asian components. Integrating genomic data with clinical data, including treatment type and survival time, has yet to reveal a discernable pattern, although Dr. Velazquez-Villarreal and colleagues are continuing this analysis.

### New Technologies

One new technology that may be effective in understanding colorectal cancer is spatial transcriptomics. The spatial transcriptomics workflow begins by fixing a tissue sample on a slide, staining with hematoxylin and eosin, and imaging the sample. Through this process, the tissue is permeabilized, allowing the RNA to diffuse onto the slide surface and bind to spatially barcoded oligonucleotides. Copy DNA (cDNA) is then synthesized from the immobilized RNA, and this is used to generate sequencing libraries. In this way, the cancer component and immune component of each sample can be identified, as well as the detection of specific tumor suppressor genes like APC and TP53, and oncogenes such as KRAS. The interactions of each component of the tissue samples are assessed, ultimately revealing the story of the tissue sample. For example, immune cells can be seen surrounding the cancer cells, carrying out an attack on the rapidly reproducing cells.

Multi-omics approaches are transforming colorectal cancer disparities research in Latinos. Whole exome sequencing, in combination with global and local ancestry data, has already revealed important associations in colorectal cancer risk, and promises many more insights. Innovative technologies such as spatial transcriptomics are also promising in their characterization of tissue samples and the resulting understanding of the important interactions therein. The integration of clinical and genomic data has enabled us to uncover intricate molecular factors contributing to disparities in colorectal cancer among Latinos.

## Breast Cancer Polygenic Risk Scores in Hispanic/Latinx/Latina Individuals

Dr. Laura Fejerman is Professor in the Department of Public Health Sciences at the University of California Davis Comprehensive Cancer Center.

### Breast cancer risk scores

Dr. Fejerman began by emphasizing that although the focus of the presentation was on polygenic risk scores and advancing the science of breast cancer in Latinas, an equally important endeavor is community outreach and engagement, which is another aspect of Dr. Fejerman’s work. The main body of the presentation included a review of genome-wide association studies (GWAS) of breast cancer in Latinas, a discussion of polygenic risk scores (PRS) for breast cancer and their transferability from original studies to diverse populations, and the results of a study testing breast cancer PRS in US Latinas and Latin American individuals.

Breast cancer is the most common cancer in women worldwide. There is variation in breast cancer incidence in the US based on race/ethnicity, with Latina individuals having lower incidence than other groups. Reported incidence rates also vary by country in Latin America and within US Latinas by nationality. For example, genetic ancestry studies performed by Dr. Fejerman and colleagues have revealed that greater percentage of European ancestry is associated with higher risk of breast cancer.

Breast cancer genetic studies are informative not only for understanding cancer biology and improving drug development, but also for risk prediction, leading to improved prevention and early detection. Although certain genetic variants are associated with increased risk of breast cancer, most cases are not associated with high penetrance mutations. Instead, variants of high frequency have been identified, each of which only contribute minimally to risk, but which may be combined to form a PRS.,,,, This PRS can then be used to inform patients how often they should be screened, and at what age screening should begin.

Currently, however, PRS used to assess risk in Europeans are only “satisfactory” in differentiating breast cancer cases and control cases, leaving much room for improvement. Furthermore, non-cancer PRS predictions used in Europeans have been shown to have limited usefulness in assessing Latina, Asian, and African individuals. Factors influencing PRS transferability include differences in heritability, differences in the effect sizes of causal variants, differences in the frequency of causal variants, differences in linkage disequilibrium (LD) patterns, and the fact that correlation between PRS and ancestry could lead to correlation between social determinants of health (SDOH) and the PRS.

### A step forward in PRS for breast cancer in Latinas

Dr. Fejerman is part of a consortium for breast cancer in Latina women that is studying 5,700 cases and 12,750 controls from the US and Latin America. A range of ancestry is represented in these cases, with Peru showing the highest percentage of Indigenous American ancestry, and the US showing higher percentages of European ancestry. Latina women in this study showed similar allele frequency and odds ratios to women in European studies.

However, Dr. Fejerman and colleagues have discovered 2 polymorphisms that are associated with Latina women of Indigenous American ancestry only, called rs140068132 and rs3778609., When these polymorphisms are added to the PRS, they make a huge difference in the area under the curve, or efficacy, of the PRS. Specifically, the European-based PRS model is less effective when considering women from Peru, a country with high Indigenous American ancestry. However, when the 2 new polymorphisms are added, the PRS becomes much more effective. In fact, adding the 2 new polymorphisms increased the efficacy of the PRS across the board, even in Latinas with more European ancestry, indicating the usefulness of this approach in the Latina population.

### Summary

The PRS used in European breast cancer studies can be useful in Latinas, but it is improved by adding Indigenous American ancestry polymorphisms. Furthermore, adding Indigenous American ancestry variants does not seem to affect prediction in highly European Latina individuals, indicating that additional Indigenous American ancestry variants are likely to improve the PRS.

One limiting factor is the dearth of patients included in the Latina GWAS studies when compared to the European studies. Because larger Latina GWAS are required, the Latin America Genetics and Genomics Breast Cancer Consortium (LAGENO-BC) has been established to share knowledge and materials to facilitate breast cancer genetics research relevant to the diverse populations of Latin America and its diaspora. With this collaboration and increase in participation, many more discoveries may be made in the field of breast cancer in Latina individuals.

## Using Molecular Epidemiology for the Study of *Helicobacter pylori*, Premalignant and Malignant Gastric Lesions

Dr. Maria Constanza Camargo is Earl Stadtman Investigator in the Division of Cancer Epidemiology and Genetics at the National Cancer Institute (NCI).

### Understanding gastric cancer

Dr. Camargo's presentation began by discussing the incidence and mortality of gastric cancer, which is the leading cause of cancer mortality globally. North and South America contribute approximately 10% of global new cases of gastric cancer every year. While the highest mortality rates in the Americas are in Peru, Haiti, Costa Rica, Guatemala, Chile, Ecuador, and Colombia, the US is considered a low-risk country, with an age-standardized mortality rate of 3.3 per 100,000. However, this risk is heterogeneous across racial and ethnic populations. While non-Hispanic White patients have relatively low gastric cancer mortality rates, Black, Asian, and Latino mortality is much higher.

Gastric cancer may be categorized by anatomical location of the tumor. Cardia cancer, located at the proximal end of the stomach, makes up approximately 18% of all gastric cancer. Noncardia cancers, which may be located in the fundus, corpus, greater or lesser curvature, antrum, or pylorus, make up approximately 82% of all gastric cancers, and are the most common subsites in Latino populations. Noncardia cancers are also strongly associated with *Helicobacter pylori* (*H. pylori*), with at least 90% of noncardia cancers linked with this infection.

According to the model of noncardia gastric carcinogenesis developed by Dr. Pelayo Correa, *H. pylori* infection first leads to benign non-atrophic gastritis. In about 10% of these cases, multifocal atrophy is observed, with or without intestinal metaplasia, which may progress to dysplasia or cancer. The progression from atrophy to cancer takes about 20 years, however, tools to intervene in that window are currently insufficient.

One potential tool showing promising results is machine learning-based prediction of gastric cancer incidence using endoscopic and histologic features. According to some international guidelines, individuals with intestinal metaplasia should be assessed every two or three years for prevention of invasive cancer development. Unfortunately, in the Americas, such screenings are not used, and this international recommendation is not followed, mainly due to the lack of local data.

### Dr. Camargo's work

Dr. Camargo and colleagues recently evaluated the proteome of *H. pylori*, and identified the humoral response antibodies against *H. pylori* in individuals with intestinal metaplasia. Although some anti-*H. pylori* antibodies have been validated as discriminatory markers, including those against the outer membrane protein 27 (Omp27) and the cytotoxicity-associated immunodominant antigen (CagA), a combination of multiple markers is needed for risk stratification.

As part of the *H. pylori* Genome Project (*Hp*GP), Dr. Camargo and over 200 colleagues collected 1011 well-characterized clinical strains from 50 countries and generated high-quality genome and epigenome sequences. The publicly available *Hp*GP dataset and the corresponding strains are a major asset for studies of *H. pylori* pathogenesis.

A genome-wide association study of gastric cancer was also recently conducted by Dr. Camargo and colleagues in Latino populations in Brazil, Chile, Colombia, Guatemala, Honduras, Mexico, Peru, and the US. Approximately 3,500 cases and 4,500 controls with gastric cancer were collected. Ongoing work is underway to develop a polygenic risk score. Dr. Camargo's group are also working to develop a multi-component biomarker approach for non-invasive diagnosis of intestinal metaplasia by combining the following: polygenic risk score, anti-*H. pylori* antibodies, atrophy-related markers, inflammation-related markers, microbiome, proteomics, metabolomics, and liquid biopsy.

Expanding their descriptive studies, Dr. Camargo and colleagues have also looked at recent trends in gastric cancer incidence, observing increases in young individuals, especially among females. Data from the Surveillance, Epidemiology, and End Results (SEER) program was used to show that noncardia gastric cancer rates have increased by 2.68% in non-Hispanic White women, by 1.63% in Latina women, and by 1.47% in non-Hispanic Black women. These findings were even more stark when looking at the corpus specifically, with increases of 6.57%, 4.83%, and 5.88% respectively.

Dr. Camargo ended by outlining a take home message. Gastric cancer is and will continue to be one of the top health problems for several populations in the Americas. A persistently high prevalence of *H. pylori* infection is present in some populations, and a rising incidence of noncardia cancer has been observed among younger individuals. Further research into the causes of gastric cancer and its evolving nature is warranted. Continued and targeted prevention efforts are needed to reduce the burden of gastric cancer, and there is an urgent need to identify discriminatory biomarkers to inform diagnosis, prognosis, and treatment.

## Advances in Our Understanding and Approach Modifiable Risk Factors for Cancers Affecting Latinos

*This plenary session occurred at 2:15 p.m., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

### Obesity and Cancer: What We Know Now About Individual- and Structural-Level Factors

Dr. Monica C. Serra is Associate Professor and Research Health Scientist in the Department of Medicine, Division of Geriatrics, Gerontology & Palliative Medicine and the Sam and Ann Barshop Institute for Longevity and Aging Studies at University of Texas Health Science Center San Antonio (UTHSCSA).

**Obesity and cancer**

Dr. Serra began by discussing obesity and severe obesity, which have become more common in the US in recent years. In 2011, 27% of adults 18 years of age or older had obesity or severe obesity, and by 2020, 32% of adults 18 years of age or older had obesity or severe obesity. Furthermore, in 2011 only 12 states had an obesity rate over 30%, while in 2021 that number had grown to 41 states. Non-Hispanic White individuals in the US have an obesity rate of 42.2%, non-Hispanic Black individuals have an obesity rate of 49.6%, and Latino individuals have an obesity rate of 44.8%.

Higher body mass index (BMI) at the time cancer is diagnosed or after having survived cancer is associated with higher risk of developing a second, unrelated cancer. Cancers associated with obesity include endometrial, esophageal adenocarcinoma, gastric cardia, liver, kidney, multiple myeloma, meningioma, pancreatic, colorectal, gallbladder, breast, and more. In fact, individuals with severe obesity are 7 times more likely to develop endometrial cancer than those who are not obese.

Increased cancer risk is not only associated with overall body obesity, but may be affected by where the excess body fat is distributed. Fat accumulation in the android region, or the abdomen, may carry a different risk than fat accumulation in the gynoid region, or the thighs. Visceral fat is also associated with a higher risk of breast cancer development than subcutaneous fat.

Potential mechanisms for the increased risk of cancer associated with obesity include the local production of hormones such as estrogen, growth factors, and inflammatory cytokines, as well as a hypoxic environment. These factors may change how cells divide and can increase the chances of mutated cell production. Insulin and insulin-like growth factor-1 (IGF-1) may also contribute to the development of colon, kidney, prostate, and endometrial cancers. Cell growth and metabolic regulators, including mammalian target of rapamycin (mTOR) and adenosine monophosphate (AMP)-activated protein kinase, may represent another potential mechanism.

In actuality, multiple of these potential mechanisms may be at play in each individual case. One further complication is that obesity can lead to difficulties in screening and management.

**Individual- and structural-level factors**

Individual-level factors contributing to the development of cancer go beyond weight, and include physical activity, dietary nutrients, consumption of processed foods, consumption of red and processed meat, consumption of sugar, alcohol consumption, the use of supplements, and more. In fact, every 10% increase in processed food consumption is associated with an increased incidence of cancer. Genetic factors also play a role in obesity, with specific genes influencing birth weight, waist-to-hip ratio, visceral adiposity, BMI, extreme obesity, and body fat.

Structural-level factors, such as socioeconomic status, access to healthcare, food environment, and urban design also play a role in cancer risk. It is known that recommended cancer screening tests and treatment guidelines reduce the risk of cancer. However, individuals with low income, low health literacy, long travel distances to screening sites, and lack of health insurance are less likely to have recommended screening and treatment. In fact, although 77.5% of employed women are up to date on breast cancer screenings, only 67.8% of unemployed women are up to date on breast cancer screenings.

Food environment includes the availability, affordability, cost, and sustainability of food. Residence in a food desert is associated with higher 5-year colorectal cancer mortality, while less food insecurity and healthier food are associated with lower colorectal cancer incidence and mortality.

Dr. Serra emphasized the difference between correlation and causation in the context of obesity and cancer. Nearly all the evidence linking obesity to cancer risk comes from large cohort studies, however, data from observational studies cannot definitively establish that obesity causes cancer. Although intervention studies are very costly, they are needed for a more decisive understanding, and should address the intersection of individual- and structural-level factors.

In summary, great challenges exist in tackling obesity and cancer risk at both individual- and structural- levels. Much more work is needed in this area to understand causation and effective interventions. Possible promising areas for research include microbiome research, a better understanding of inflammation and immune response, precision medicine approaches, lifestyle interventions, and therapeutic approaches.

## Using an “Exercise is Medicine” Approach among Latino Cancer Survivors: Challenging the Research Gap

Dr. Christina M. Dieli-Conwright is Associate Professor of Medicine at Dana-Farber Cancer Institute and Harvard Medical School.

**Exercise and cancer**

Dr. Dieli-Conwright began by defining exercise oncology as the utilization of exercise or physical fitness to enhance the lives of people diagnosed with cancer or at risk of developing cancer. Exercise oncology research has evolved over the last 100 years, beginning with the discovery in 1921 that cancer mortality is inversely proportional to muscular strength. In 1952, the first clinical trial evaluating exercise for lymphedema following mastectomy was conducted. The first American College of Sports Medicine (ACSM) roundtable was convened in 2010, leading to the publishing of exercise guidelines, which were updated in 2019. The number of research manuscripts focused on exercise oncology has greatly increased in the years since the ACSM publications.

The 2010 roundtable's published Exercise Guidelines for Cancer Survivors recommended 150 minutes of moderate-intensity physical activity per week, or 75 minutes of vigorous-intensity physical activity per week. Updated 2019 guidelines changed recommendations to 30 minutes of moderate intensity physical activity, 3 times per week. Similarly, 2010 guidelines recommended resistance exercise 2 or more days per week, involving the 8 major muscle groups. Updated guidelines specified 2 times per week, 30 minutes per session, 2-3 sets, involving large muscle groups.

### Disparities in Latino cancer patients

Cancer health disparities in the US are influenced by behavioral factors, including tobacco use, diet, excess body weight, and physical inactivity. Many of the cancers with the highest incidence and mortality among Latino individuals are cancers that are known to be positively influenced by engaging in a physically active lifestyle. These include prostate, colon and rectum, and kidney and renal pelvis cancers, which represent 3 of the 4 most common cancers in Latino males; and breast, uterine corpus, and colon and rectum cancers, the 3 most common cancers in Latino females.

Existing energy balance research is largely focused on non-Hispanic White populations, despite the higher rates of obesity, physical inactivity, and comorbidities observed in minority groups. Exercise interventions specifically for Latino cancer survivors are sparse. Walking and aerobic plus resistance exercise have been studied, but to date no trials exist looking at resistance exercise alone among Latino participants. Studies that have been performed are also mostly home-based, or conducted in community centers and churches with little supervision. Despite limitations, these studies have shown that exercise can increase moderate to vigorous physical activity minutes, cardiorespiratory fitness, muscle strength, and quality of life, while reducing fatigue.

Barriers to energy balance interventions for Latino populations can be divided into barriers for researchers and barriers for participants. For researchers, the following barriers exist: (1) the urban location of most research institutes limiting rural or suburban participation; (2) uneven distribution of minority populations making access to participants more difficult; and (3) a lack of understanding of the decline of study participation. Participants also face significant barriers: (1) limited access to resources, (2) extended transportation time, (3) high family needs, and (4) a lack of understanding of the intervention. Potential facilitators to address these barriers include multi-center trial designs facilitating participation from various geographic locations, survey or focus-group studies to comprehend unique barriers and preferences of intervention, more accessible intervention design such as remote-based delivery (e.g., telephone, online format), and culturally tailored intervention methods including the use of the local community and engagement of family members.

### Latino exercise oncology research

Dr. Dieli-Conwright and colleagues have initiated research into several interventions. The first established that exercise for 16 weeks can reduce metabolic syndrome in sedentary, overweight or obese breast cancer survivors, more than half of which were Latina. Another study showed significant improvements in cardiometabolic, physical, and psychosocial health outcomes among sedentary, overweight or obese breast cancer patients through high-intensity interval training; 75% of participants were Latina.

Lessons learned about conducting a clinical exercise trial in minority cancer survivors included the following: all staff were bilingual, supervised and flexible exercise sessions were offered, recruitment involved collaboration with medical oncologists, testing measures were carefully interpreted, and many follow-up calls were given to ensure participation. Furthermore, not every culture perceives exercise as commonplace, so sensitivity must be shown.

Future work by Dr. Dieli-Conwright and colleagues includes the Reducing Metabolic Dysregulation in Obese Hispanic/Latina Breast Cancer Survivors using Physical Activity (ROSA) trial, the Testing Home-based ExeRcise Strategies to Improve Exercise Participation and CardioVascular Health in UndersErved Minority Patients with Cancer Undergoing Chemotherapy (THRIVE) trial, and the Exercise to Enhance Cardiovascular Health among Black Prostate Cancer Patients with Androgen Deprivation Therapy (POWER) trial. Because exercise is medicine, and exercise is feasible among Latino cancer patients, exercise may offset cancer health disparities. Multi-center, culturally tailored, randomized controlled trials are needed to further this work.

## Improving Smoking Cessation for Latinos Using a Community-Based Approach

Dr. Anapaula Cupertino is Professor of Public Health Sciences and Oncology at the University of Rochester Medical Center and Wilmot Cancer Institute’s first Associate Director of Community Outreach, Engagement, and Disparities.

### The JUNTOS Center for Advancing Latino Health

Dr. Cupertino’s presentation began by discussing tobacco-related disparities among Latino individuals, specifically in the area around Rochester, New York, where 17% of non-Hispanic White individuals are smokers, compared to 21% of Latino individuals. This may be associated with the high number of Latinos of Puerto Rican descent in the Rochester area; the Study of Latinos (SOL) study identified high smoking rates in Puerto Rico. This illustrates the importance of tailoring interventions to the target population of a local area, taking into consideration ancestry, socioeconomic status, and cultural considerations.

Although smoking cessation programs, including behavioral counseling and medication, are known to be effective, tailoring these interventions to specific populations can be difficult. In 2007, Dr. Cupertino and colleagues began the JUNTOS Center for Advancing Latino Health in Kansas City, Kansas in order to engage the Latino community there. The community advisory board was instrumental in shaping the work.

In order to engage the community effectively, trust had to be established, and the needs of the community had to be addressed. The highest priority among Latino community members in the Kansas City area, for example, was immigration status and diabetes. By focusing on these areas, Dr. Cupertino and colleagues were able to establish the necessary trust to push for studies addressing smoking cessation. This trust-based approach is in contrast with the typical approach of only engaging communities when participant recruitment is needed. Instead, community leaders and experts must work together to develop the intervention content and modes of delivery.

### Text- and app-based approaches

One approach that was unsuccessful among the Kansas City community was phone-based counseling for smoking cessation. Instead, community feedback indicated that Facebook or WhatsApp were more commonly used and were more comfortable mediums. Funding and partnerships to develop an app-based intervention were difficult due to inherent biases about Latino levels of literacy. Finally, a partnership was initiated with Agile Health Solutions, a company that had developed a text message-based smoking cessation program in Australia and England. However, previous Latino engagement with this program was less than one percent.

The first study after the partnership of JUNTOS and Agile Health involved 20 participants and resulted in 30% smoking cessation, indicating that concerns over Latino literacy were wildly overblown. Furthermore, whereas previous text-based programs averaged an interactivity of 11 messages, the study with Latino participants averaged an interactivity of 38 messages. These messages were also highly personalized and highly supportive, indicating an effectiveness among the Latino community not seen elsewhere.

One complaint from participants was the inaccuracy of the translation of the text messages. To address this, the National Institutes of Health (NIH) funded a more appropriate linguistic adaptation, which was then used to engage larger populations, yielding similar cessation rates. Although the value of the linguistic adaptation may be questioned in light of the similar results, the trust built by listening and taking action on community concerns was invaluable.

### A randomized controlled trial

A randomized controlled trial was conducted in which 228 participants were randomized to receive the mobile text message- and web-based interactive intervention, or educational material. Both groups had access to medication, but the text-based intervention was individualized to assess coping strategies, when the participants smoked, tools during withdrawal, and more. Text messages were also adjusted to include more information about nicotine replacement therapy (NRT), familismo, and stress, at the request of community members. A relapse track was also developed for those who were not able to quit at the first intervention.

Eligibility for participation included being Latino, more than 21 years of age, and smoking at least 3 days per week. The majority of smoking cessation clinical trials require English proficiency, so the availability of this intervention in English and Spanish meant much more Latino inclusion. In fact, 71% of participants in the randomized controlled trial chose the Spanish option. Results of the study showed that 31% of participants randomized to receive text message- and web-based intervention self-reported quitting, with very high engagement. Some participants even sent as many as 684 messages.

Dr. Cupertino and colleagues seek to use this intervention beyond the US, and into Mexico, Central America, and the rest of Latin America. Another area of future research is to engage with HIV patients, and develop a program for vaping among young Latinos as well. Further work in progress includes an intervention for transgender smokers in Argentina.

# Leveraging Technology to Enhance Research, Cancer Control and Prevention

*This breakout session occurred at 4:00 p.m., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Advances in Evidence-based Digital Solutions for Supporting Latino Cancer Patients

Dr. John Piette is Professor in the School of Public Health, and Director of the Center for Managing Chronic Disease (CMCD) at the University of Michigan.

### Cognitive behavioral therapy

Dr. Piette's presentation began by discussing how cognitive behavioral therapy (CBT) can be used for Latino cancer patients. CBT is the most common evidence-based intervention for cancer patients struggling with mental health, symptoms, stress, and sleep. In cancer patients, CBT has been shown to help manage distress and pain, alleviate insomnia, manage fear of cancer recurrence, and reduce emotional distress and improve quality of life. In Latino populations in particular, CBT has also been shown to be effective, specifically in survivors of systemic violence and in individuals with emotional disorders.

The use of technology with CBT has been validated, with video sessions shown to be as effective as in-person meetings for individuals with anxiety. Therefore, CBT is useful in cancer, in Latino patients, and is compatible with technological delivery. Dr. Piette's own work involves the Rompiendo Fronteras project, delivering CBT to patients in Honduras via video sessions which may be conducted at a distance, even as far as the US.

A typical CBT program for cancer symptom management would involve 10 sessions covering rationale for treatment, defining treatment goals, working with healthcare teams, breathing, relaxation, unhelpful thoughts, living with cancer symptoms, promoting pleasant activities, sleep skills, and relapse prevention. Traditional patient barriers to such a program, however, include transportation, health and mobility problems, and scheduling. Systemic barriers include scarcity of therapists, challenges of supervision, and inadequate payment.

### Artificial intelligence

Another technology discussed by Dr. Piette is artificial intelligence (AI), specifically in the realm of diagnosis, prognosis, and staging. Machine learning can be extremely useful in the identification of pathology slides, for example. Recommender systems, such as those used by Netflix and Amazon to recommend products, may also be useful in helping cancer patients navigate issues that are most important to them in their specific situation, prioritizing population- or patient-specific treatment goals.

AI may also be effective through the use of natural language processing (NLP) like ChatGPT and others. Communication between cancer patients and their physicians is known to be lacking, especially when language barriers are a factor. Embarrassment and emotionally charged topics can cause patients to withhold information as well. One use of NLP may be to analyze patient-clinician interactions to assess whether the clinician is dominating the conversation, or whether the patient is able to communicate in a more egalitarian way. NLP can also analyze whether providers are using best practices: affirming the patient, encouraging the patient, using open-ended questions, and noting emotion. This tool can be useful in improving the quality of patient-clinician communication.

In CBT intervention programs, although many patients need the full treatment schedule (e.g., 10 weeks), many others show significant improvement in a shorter time frame. Identifying which patients need less intervention, therefore, could alleviate clinician burden, and free up resources for the treatment of more patients. Reinforcement learning allows AI to learn from data about each individual, enabling prediction about what interventions are needed, and allowing for flexibility in visit number, visit length, and type of communication. Up-to-date feedback about each patient, combined with the patient's history, gender, primary language, and more, allows for greater and greater intelligence about patient needs, and about the allocation of clinician resources.

A randomized comparative effectiveness trial conducted by Dr. Piette and colleagues compared patients receiving individualized AI-supported CBT intervention for pain care with a control group receiving the standard full CBT program. Results showed that patients receiving individualized AI-supported care achieved outcomes that were at least as good as standard care. Importantly, however, AI-supported care required less than half of the therapists' time. This indicates that an AI-supported approach could allow for the treatment of twice as many patients, an important consideration given the many barriers to treatment that involve clinician resources.

### Adapting evidence-based interventions

Dr. Piette closed by discussing the adaptation of evidence-based interventions in the Latino cancer context. Because most evidence-based interventions are not focused on Latino cancer care, these interventions must be adapted for a new audience and purpose. The process of adaptation should include input from two contingents: members of the target community and experts involved in the original intervention. First, community end-users, community health professionals, and community administrators can indicate areas that need to be modified in order to engage a new audience in a culturally sensitive way. However, input from those involved in the original intervention might also be useful. Intervention experts, relevant clinicians, community experts, and delivery mode experts who are familiar with the proven intervention can indicate which areas were most impactful and needed, identifying and retaining key elements. When input can be integrated from target community end-users and original intervention participants, adaptation for Latino cancer patients is most effective.

## mHealth Smoking Cessation for Primary Care and Cancer Patients

Dr. Patricia Chalela is an Associate Professor in the Population Health Sciences Department and the Associate Director for Education and Training Programs at the Institute for Health Promotion Research at UT Health San Antonio.

### The Quitxt smoking cessation program

Dr. Chalela's presentation focused on the Quitxt smoking cessation program, which is implemented at UT San Antonio in collaboration with Dr. David Akopian and his team at the University of Texas at San Antonio. Quitxt was developed with the goal of reaching Latino young adult smokers living in South Texas and was promoted through social media and community outreach. Although several social media platforms have been utilized, Facebook has so far been the most effective in generating participation in the program.

Phase 1 of the program involved the enrollment and evaluation of 798 Latino participants, 21% of which self-reported being smoke free at 7 months. Based on these results, two additional grants were awarded, and phases 2 and 3 of the Quitxt program were initiated. In phase 2, the primary population was expanded to include African American and non-Hispanic White young adult smokers living in South Texas.

Dr. Chalela and colleagues also developed the first Facebook Messenger chat intervention tailored to young adults. Facebook Messenger allows more graphic content such as GIFs and memes, which are appealing to young adults. The Messenger app also allows participants to choose from several response options, instead of typing in their response, making it more user friendly. Links to videos are also visible as animations, instead of just the URL link in a text message.

In phase 3, the Quitxt program was adapted to the patient population of the Primary Care Center and the Mays Cancer Center at UT Health San Antonio. Healthcare providers (HCPs) have unparalleled access to smokers, with about 70% of smokers visiting primaryHCPs each year. Furthermore, research shows that smokers consider their physician's advice an important motivator for quitting smoking. To facilitate easy access to Quitxt by HCPs, the program was integrated into EPIC, the electronic health records (EHR) system.

Every patient is asked about tobacco use. If the patient is a current tobacco user, the EPIC Quitxt Best Practice Advisory (BPA) banner prompts HCPs to provide quitting advice, offer nicotine replacement therapy (NRT) if needed, and recommend enrollment in the Quitxt program. Once the program is selected in EPIC, follow-up by the program patient navigator is activated. The patient navigator conducts follow-ups and provides support, motivation, positive reinforcement, and help enrolling in Quitxt if needed.

Quitxt enrollment cards help providers start the conversation about enrolling in Quitxt and include simple instructions on how to enroll by texting a code word to the program phone number or by scanning a QR code. Instructions on how to enroll in the program are also part of the patient's after-visit summary. The patient navigator's follow-up notes in the EHR keep HCPs informed about patients' progress and HCPs can provide support as needed. A vaping protocol is also being finalized for use at both treatment sites.

### Lessons learned from the Quitxt program

Some of the lessons learned through the implementation of the program include the following: pretesting is critical, and simplification is important to keep participants engaged. It is essential to engage key players early, starting with program design, i.e., program champions, the Chief Health Informatics Officer, and the EPIC team. Program champions play a key role in program promotion and implementation. Adaptability to unexpected circumstances is vital. The COVID-19 pandemic impacted the implementation of the program in many ways. The Quitxt team acted quickly and adapted CME training for HCPs to a short 8-minute video. A patient navigator was integrated into the program to follow up with participants and reduce HCPs' burden. Patients who are not ready to quit are more likely to make a quit attempt if their HCPs recommend it. In this regard, EPIC notes have been very helpful in keeping HCPs informed so that they can provide positive reinforcement and support to patients as needed. Keeping HCPs engaged through regular reports and quarterly presentations at meetings can also be helpful. Finally, addressing technical issues quickly for both patients and HCPs is imperative, as well as listening to patient feedback and refining the program accordingly.

Integrating Quitxt into the healthcare setting greatly increases the accessibility and utilization of a bilingual evidence-based smoking cessation program among primary care and cancer patients. Quitxt can be easily replicated and represents an affordable approach to reaching tobacco-using patients, producing a public health impact, and reducing healthcare costs and tobacco-related diseases and mortality. Phase 4 of the intervention is currently underway and involves a 2-group parallel randomized controlled trial to assess the effectiveness of Quitxt on smoking cessation, comparing Quitxt to a traditional abbreviated text message intervention.

## Mobile Health to Improve Cancer Prevention in Latino Patients

Dr. Yasmin Genevieve Hernandez-Barco is Director of the Pancreas Program at Massachusetts General Hospital and Instructor at Harvard Medical School.

### Cancer in Latino populations

The objectives of Dr. Hernandez-Barco’s presentation included the following: to understand the barriers to effective cancer screening and prevention in Latino patients, to identify potential mobile-based solutions to overcome these barriers, and to think about how to leverage existing technology to help improve health for Latino patients. The presentation began by sharing several case studies.

In one example, a 60-year-old Latina woman with no past medical history noticed a bruise on her left breast in 2013. She was diagnosed with estrogen receptor (ER)-positive, progesterone receptor (PR)-negative, human epidermal growth factor receptor 2 (HER2)-positive adenocarcinoma, but the patient was uninsured and without employment and refused care due to feelings of shame and embarrassment. After 2 years the tumor ulcerated through her skin leading to bleeding and foul smell. The family worked together to pay for private coverage, and she was maintained on 3 years of Herceptin$^{©}$ (trastuzumab) infusions. After deciding to self-discontinue in 2020, the tumor grew back, and in 2022 she developed a metastatic fracture of her left arm, leaving her incapacitated. She was enrolled in hospice and passed away at home 4 months later.

Cancer is the leading cause of death among Latino patients, with 42,700 deaths annually. Prostate, breast, and colon cancer are the most common among Latino individuals, all of which are detectable through cancer screening. There are significant disparities in cancer screening in Latino versus non-Hispanic White individuals, many of which are driven by social determinants of health: economic stability, education, social and community context, health and health care, and neighborhoods and built environment.

Barriers to cancer screening include financial considerations, such as access to health insurance and obtaining transportation or taking time off work. A lack of understanding of medical recommendations and the rationale behind them can also be a barrier for non-English speakers. Finally, cultural considerations, including the use of natural remedies and the value of *familism* (putting the family above oneself), may also present as barriers.

The core tenets for cancer prevention include avoiding tobacco, limiting alcohol, following a healthy diet, reducing air pollution, avoiding excess sun, receiving vaccinations, and undergoing cancer screening. Although some of these tenets may be inaccessible for some populations, age-appropriate cancer screenings should be an emphasis for intervention.

### MobileHealth and Latino cancer patients

MobileHealth (mHealth) is defined by the World Health Organization (WHO) as a medical and public health tool supported by mobile devices such as mobile phones, personal digital assistants, patient monitoring devices, and other wireless devices. Advantages of mHealth include low cost, ease of use, the ability to frequently contact patients, and the ability to tailor the technology to patients' social and demographic profiles. Access to smartphones is similar across all demographic groups, and mHealth has been shown to improve cancer screening behavior in the Latino population.

However, there is a paucity of research on the use of mHealth in Latino individuals. Furthermore, very few mobile apps are available for mHealth in Spanish. The limited existing studies have shown that a Spanish touch screen interactive explanation of the usefulness of colorectal cancer screening, given in a clinician's office, can be useful in increasing screening rates. Spanish text message reminders can also be effective in promoting breast cancer screenings.

An intervention initiated by Dr. Hernandez-Barco and colleagues used text message reminders to improve the no-show rate for colonoscopies. Patients scheduled for a colonoscopy received regular reminders, including a pre-procedure checklist, medication instructions, a reminder to start a clear liquid diet, instructions on what to bring, and post-care instructions. The text messages were in Spanish, and were accompanied by instructional videos, also in Spanish. A significant decrease in no-show rates was observed among individuals receiving the text messages, and bowel preparation was also significantly improved. The level of patient engagement with the text messages was also correlated with improved no-show rates.

The majority of studies to date are based on providing education regarding the importance of cancer screening to Latino patients, and these interventions are primarily provided in clinics. This leaves an enormous need for app-based resources. Although there are thousands of apps which exist for cancer prevention, only a small percentage exist in the Spanish language or are specifically aimed at Latino patients. Video-based learning appears to be most helpful, and text-based interventions represent a clear opportunity for growth with high engagement and success across several cancer types.

## Strategies for Inclusive Engagement of Latinos in Cancer Clinical Trials

*This breakout session occurred at 4:00 p.m., Thursday, Feb. 22, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

---

### The NCI Community Oncology Research Program: Opportunities to Increase Latino Participation in Clinical Trials

Dr. Brenda Adjei is Associate Director of the Office of Healthcare Delivery and Equity Research at the National Cancer Institute (NCI) Center for Cancer Research.

**The NCI Community Oncology Research Program**

Dr. Adjei's presentation began with a discussion of Latino participation in cancer clinical trials. Diversity in clinical trials is critically important because it generates biomedical knowledge relevant to all, builds trust and trustworthiness, and contributes to reductions in health disparities and equitable research participation. Current underrepresentation in clinical research is due to multilevel barriers and requires tailored, multi-component evidence-based strategies.

The presentation involved a description of the National Cancer Institute's (NCI) Community Oncology Research Program (NCORP), NCORP's disparities integration activities, an assessment of NCORP's disparities resources, and a summary of results and future opportunities. NCORP is made up of 46 sites, 32 of which are community sites and 14 of which are minority/underserved community sites. The minority/underserved community sites have at least 30% of their patient population from racial and ethnic underserved populations, or rural residents. Within the Program, 7 research bases develop and coordinate clinical trials and cancer care research, with participation from over 1,000 clinical practices across the country.

Disparities research is an important emphasis and is integrated into every aspect of NCORP's activities, specifically accrual, education, and mentoring. The Disparities Integration Emphasis Group (DIEG), comprised of NCORP investigators, leverages NCORP's strengths, expertise, and experience to enact real change in the equity of cancer trial participation. The goal of the DIEG is to increase the portfolio of disparities research and ensure equitable representation of diverse racial/ethnic, rural, and other underrepresented populations in NCI clinical trials. Strategic objectives include a portfolio analysis to examine and evaluate current NCORP research, a research studio to advise on specific disparities-related research questions, and a resource matrix to provide disparities-focused best practices, guidance, documents, expert contacts, and resources from the NCORP network.

The resource matrix aims not only to create a repository of disparities focused resources, expertise, and other assets, but also to understand what resources NCORP sites and research bases have, need, and could contribute to support DIEG goals. The matrix has approached this mandate by collaboratively designing a Request for Resource Information (RRI) survey that focused on site and research base administrators and assesses outreach populations, barriers, and resource needs/availability. The survey was fielded between April and July 2023 and used a thematic analysis and team-based approach to resolve discrepancies.

### Request for Resource Information results

Of the 46 NCORP sites, 34 (74%) submitted RRIs, with 25 reporting significant experience with Latino clinical trial outreach. Most of the responses were from site administrators (60%), with participation from research nurses, coordinators, and other research team members as well. Of the reported clinical trials recruitment barriers reported, the most frequently cited was travel and transportation, with 71% of surveys mentioning this barrier. Further reported barriers included low health literacy, cost or financial considerations, patient-reported barriers of time burden and childcare cost, and limited English proficiency.

Some themes emerged in the RRI site-reported strategies to address these barriers. For improving recruitment, the most frequently reported strategy was pre-screening activities, with 21% of sites mentioning this strategy. Community outreach, multilingual engagement, communication strategies, and fostering trust were also reported. In fact, fostering trust was the most frequently reported strategy in addressing retention (23%), with continuous engagement, multilingual engagement, and study-specific materials also mentioned. Community outreach (26%) and education (26%) were the most frequently reported strategies for improving engagement.

The RRI survey involved some limitations. First, the survey was an assessment of site experiences, and was not administered for research purposes. Data from the survey was also elicited via open ended questions with provided examples which may have resulted in biased responses regarding challenges linking barriers and resource gaps/needs with population groups. Finally, data are based on the perspectives of administrators as the primary respondents due to the high turnover within clinical teams and the time burden for clinical research staff.

Multilevel inclusive research approaches are needed to address disparities in Latino cancer clinical trials. In fact, changes are needed in organization-level practices, community-level practices, workforce-level practices, and patient-level practices. A strong institutional commitment is fundamental to enacting change at each of these levels, and at all levels using a holistic approach.

## The SWOG Latin America Initiative: Addressing Cancer Disparities Throughout Latin America and the United States

Dr. Paula A. Cabrera-Galeana is Professor in the Breast Cancer Unit at the Instituto Nacional de Cancerología in Mexico City.

### Cancer clinical trial disparities in Latin America

Dr. Cabrera-Galeana's presentation began by discussing the incidence of cancer worldwide, with the highest rates occurring in the US and Europe, although gaps in cancer registration exist in many low- or middle-income countries. Cancer mortality, however, is higher in many low- and middle-income countries, although not in Mexico, where current policy prevents accurate reporting of cancer mortality. In high-income countries, oncology medicines account for a small share of total cancer expenditures, while in lower-income countries, these pharmaceutical expenses account for a larger share, up to 40-60%. Total health spending per capita is over $12,000 in the US, while that number is less than $2,000 in Mexico.

Any government policy that seeks to address these disparities has to be patient-centered. Furthermore, the pharmaceutical industry and providers and payers must be considered and engaged in wide-ranging policy initiatives. Latin American countries are also in need of strong policy advocates to enact change.

Breast cancer mortality is influenced by many factors. Government funding for care is one of the biggest factors, as is incidence. Stage at diagnosis also influences overall survival, with earlier stage diagnosis leading to higher survival. Individuals with breast cancer diagnosed at an early stage in Mexico had a 5-year survival of 89.0%, while those diagnosed at a locally advanced stage had a 5-year survival of 69.6%, and those diagnosed at a metastatic stage had a 5-year survival of 36.9%. Early diagnosis, therefore, through breast cancer screenings, must be a priority. Access to quality treatment and biological features are also factors in overall survival.

Breast cancer occurs 10 years earlier in Latin American populations when compared with non-Hispanic White populations. In fact, although the US National Cancer Center defines the adolescent and young adult (AYA) population as ages 15 to 39, some Latin American countries define the AYA population as under 24, or even younger.

Addressing disparities in cancer outcomes begins with clinical trials. However, although many clinical trials take place in the US, Europe, and China, comparatively few clinical trials are based in Latin America. Clinical trials in Latin America are needed to convince governments to spend money on proven cancer treatments. Latin American trials can also shed light on Latino cancer in the US, where Latino individuals represent the largest minority and are projected to make up almost one quarter of the population by 2050.

### SWOG Cancer Research Center

The Southwest Oncology Group (SWOG) is a collaborative group of cancer centers that develops clinical trials asking academic questions. Founded in 1956 by Texas pediatrician Grant Taylor, collaborations with INCan Mexico began in 2010, followed by other Latin American countries. SWOG's Latin American Initiative (SLAI) strongly believes in education and training, and encourages Latin American members to conduct their own trials while also participating in SWOG studies. In fact, SWOG carefully chooses and promotes trials that have minimal barriers in Latin America.

Dr. Cabrera-Galeana's employer, the National Cancer Institute (NCI) in Mexico, is a SWOG partner and performs approximately 200,000 medical consultations with approximately 5,500 newly diagnosed patients per year. NCI's personnel, including 26 staff physicians and 32 fellows, are being trained to participate in SWOG research.

Future goals of the NCI-SWOG collaboration include increasing protocols, increasing awareness of the available potential protocols, increasing awareness of other SWOG opportunities, and increasing participation in SWOG committees. Once NCI participation in SWOG trials is more comprehensive, NCI seeks to increase recruitment and reduce institutional approval times, as well as increase the access to high-cost drugs. In Latin America, thanks to the work that SWOG is involved in, better cancer care has been achieved, better data has been generated, and better trained doctors are serving cancer patients.

## Building Capacity for Transformative Cancer Care in Latin America: Integrating Smoking Prevention and Cessation into Oncology Care

Dr. Irene Tamí-Maury is an Assistant Professor in the Department of Epidemiology at The University of Texas Health Science Center at Houston (UTHealth).

### Smoking in Latin America

Dr. Tamí-Maury began by discussing the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC), a major public health agreement fighting against the tobacco epidemic. Unfortunately, the US was one of only a handful of countries that did not participate in the WHO FCTC. The WHO FCTC implemented the MPOWER package, a set of six key tobacco control measures: Monitor tobacco use and prevention policies, Protect people from tobacco smoke, Offer help to quit tobacco use, Warn about the dangers of tobacco, Enforce bans on tobacco advertising and promotion and sponsorship, and Raise taxes on tobacco.

Many countries, however, have insufficient resources to accomplish these goals, especially in the area of helping tobacco users quit. Standardized, evidence-based tobacco cessation programs are limited or lacking. In many Latin American countries, smoking prevalence is higher than in the US as the tobacco industry turns its attention to countries with fewer regulations.

### The STOP training program

Dr. Tamí-Maury and colleagues have performed extensive research on tobacco and nicotine addiction in Latin America and have discovered that although many clinicians at cancer centers feel strongly about the importance of implementing smoking cessation interventions, they feel ill equipped when it comes to programs and resources to support patients with their quitting efforts. The efficacy of Dr. Tamí-Maury's Smoking Cessation Training Program for Oncology Practice (STOP) was evaluated in Colombia and Peru from 2018 to 2023. The STOP Program trained cancer care providers to deliver adequate counseling and pharmacotherapy. The training was a combination of online and in-person sessions, and included 5 modules on smoking prevention and cessation followed by 3 assessments over the following 6 months to determine participants' retention and other training outcomes such as their knowledge, attitude, self-efficacy, and practices toward smoking, smoking prevention, and cessation services.

At the 1-month assessment, knowledge, attitude, self-efficacy, and practice scores increased from baseline. However, over the next few months, clinicians reported returning frequently to their notes from the training, and needing a tool to quickly access knowledge and support that may have been forgotten since the training ended. In response to this need, a web-based algorithm was provided at the 3-month mark to support the participating clinicians. This intervention yielded increased self-efficacy and practice scores from month 1 to month 3, and from month 3 to month 6. Knowledge scores remained approximately the same throughout.

In order to streamline access to the web-based algorithm and to facilitate access to this tool even when internet access is limited, the Decision-T app was developed, containing all resources of the web-based algorithm in a more accessible format. Conversation prompts were also added to help clinicians initiate discussion about important topics involved in smoking cessation. Upon assessment by HIV care providers, the Decision-T assessment was able to be administered in around 5 minutes, with a System Usability Scale (SUS) score of 87.5, indicating high usability. Similar outcomes were achieved by cancer care providers, primary care providers, and dental care providers who subsequently tested the Decision-T app.

### Lessons learned from the STOP Program for smoking prevention and cessation

Integrating smoking prevention and cessation into clinical care in Latin America is possible. However, it is essential to consider unique opportunities and challenges existing in each Latin American country before implementing these programs.. Collaborative efforts with local stakeholders make sustainable solutions for preventing and controlling smoking in Latin America possible. Successful adaptation of interventions to this area of the world is not merely about translating existing programs that have been successful in the US, but includes cultural adaptation as well. Digital health solutions like the Decision-T app can improve access to care, increase efficiency, and reduce costs for smoking prevention and control.

The Latino population is the fastest-growing minority in the US, with projections indicating that 1 in 4 individuals living in the US will be Latino by 2060. More than 20 countries of origin are represented among US-based Latinos, including 62% from Mexico, 10% from Central American countries, 9% from Puerto Rico, and 6% from South America. Approximately 12% of the population of California and Texas speak Spanish at home and report speaking English "less than very well." Clearly, smoking cessation interventions targeting Spanish speakers, as well as programs that are sensitive to a wide array of Latin American cultures, are vital.

## Cancer Center Priorities for Addressing Latino Cancer Health Disparities: A Fire-side Chat with Cancer Center Directors

*This special session occurred at 9:00 a.m., Friday, Feb. 23, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

Dr. Yolanda Sanchez is the Maurice and Marguerite Liberman Distinguished Chair in Cancer Research, Professor in the University of New Mexico (UNM) Department of Internal Medicine Division of Molecular Medicine, and UNM Cancer Center Director and Chief Executive Officer.

Dr. Sanchez discussed the University of New Mexico Comprehensive Cancer Center (UNMCCC) and its mission to reduce the cancer burden and overcome the tremendous cancer health disparities in New Mexico and the Nation. The UNMCCC serves a unique catchment area with multiethnic populations through respectful, bidirectional engagement and communication. New Mexico has the 3rd highest percentage of American Indians in the US, 23 Sovereign Tribes/American Indian Nations, and the highest percentage of Hispanics/Latinos in the US. Indigenous American Indians and Hispanics share striking similarities in cancer health disparities.

The New Mexico Cancer Research Alliance partners with community-based health systems and oncology providers and conducts ongoing research, education, and training partnerships with American Indian Pueblos and Nations and Hispanic communities. The UNMCCC also partners with Lovelace Biomedical Research Institute for complementary lung cancer prevention, screening, and treatment, as well as tobacco and e-cigarette research. Community outreach and engagement is integral to the work of the UNMCCC, with the goal of impacting and overcoming the disparate patterns of cancer incidence and mortality in New Mexico's multiethnic, rural, and underserved populations. The UNMCCC also serves as a conduit between the Center and these communities by facilitating cancer research on catchment area priorities through respectful bidirectional engagement.

Dr. Ruben Mesa is President of Enterprise Cancer Service Line Atrium Health, Executive Director of the National Cancer Institute (NCI)-designated Atrium Health Wake Forest Baptist Comprehensive Cancer Center, and Vice Dean for Cancer Programs at Wake Forest University School of Medicine.

Dr. Mesa began by discussing the history of the National Cancer Institute (NCI), which was developed after President Nixon declared the War on Cancer in 1971. The thinking at the time was that cancer would be cured relatively quickly, but clearly the variability of the tumors and patients were severely underestimated. In this way, cancer centers' focus on working with communities can yield a fuller understanding of many of the factors contributing to this variability. Although Latino individuals have particularities that should be understood in the context of cancer, the heterogeneity in the Latino populace makes community work even more vital to understanding prevention, control, treatment, and survivorship.

As one of the first Latino Cancer Center Directors, Dr. Mesa emphasized the importance of diversity in cancer leadership. The Wake Forest Baptist Comprehensive Cancer Center, of which Dr. Mesa is the director, has specialized in implementation science and cancer control for the past 50 years. They have recently partnered with Atrium Health to become one of the largest cancer centers in the country. The Cancer Center also now has cutting edge care-at-home programs, in which not only is cancer care is provided in the home, but initiatives to combat food insecurity, and partnerships with organizations and government programs for continued care as well.

# Expanding the Oncology Workforce

*This session occurred at 10:00 a.m., Friday, Feb. 23, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

## Inclusion in Action: Breaking Open the Leaky Pipeline to Create Pathways & Design Spaces that Improve Representation

Dr. Idalid "Ivy" Franco is Director of Equity, Access, and Inclusion, and works in the Department of Radiation Oncology at Brigham and Women's Hospital and Dana-Farber Cancer Institute at Harvard Medical School.

### The effect of oppression on workforce representation

Dr. Franco's presentation began by looking at the historical context and systemic barriers to recruitment, retention, and professional success of a representative workforce. This historical context started with American slavery, followed by years of segregation, laying a foundation of institutionalized and internalized racism. This racism lies in the intersectionality of multiple social forces, identities, and ideological instruments through which power and disadvantage are expressed and legitimized.

Implicit or unconscious bias is a form of bias that occurs automatically and unintentionally but nevertheless affects judgments, decisions, and behaviors. Research has shown implicit bias can pose a barrier to recruiting and retaining a representative scientific workforce., Microaggressions represent another barrier to representation, and these come in various forms. Microassaults are verbal or non-verbal acts that attack a person's group or identity or harm them through name calling, avoidance, and/or discriminatory actions. Microinvalidations are comments or actions that disregard, exclude, or dismiss the thoughts, feelings, and/or experiential reality of a particular group. Microinsults are subtle snubs or humiliations that convey a stereotype, insensitivity, or a demeaning message about a person's group identity. Microassaults, microinsults, and microinvalidations may be reflected in the policies, culture, and climate of the workplace.

Recurrent exposure to perceived discrimination adversely impacts performance, mental health, achievement, self-esteem, physical health, and advancement. In academic medicine, discriminated groups are less likely to achieve advancement in salary promotions, leadership positions, funded grants, accepted publications, and academic rank. Historically there has been a lack of access to resources, education, understanding of the system, mentorship and sponsorship, promotion and recognition, and role models.

Based on 2023 data, Latino individuals have the lowest representation quotient of medical students enrolled at US medical schools compared to their corresponding percentage of the US 2023 population (12.7% vs 19.1%). These numbers are even worse in the field of oncology, where only 4.7% of practicing oncologists self-identify as Hispanic/Latino, a fact that is even more troubling in light of the fact that cancer has become the leading cause of death among

Hispanic/Latino communities. This underrepresentation underscores the importance of creating pathways, spaces, and opportunities toward a more equitable workforce centered around research and the clinical needs of a growing community.

Across the country, state lawmakers are proposing bills to limit diversity, equity, and inclusion (DEI) programs at state-funded institutions. Currently there are more than 30 bills that could impact a wide range of initiatives, from defunding DEI offices and officers to removing diversity statements from hiring practices. Nearly half of the states in the U.S. have either proposed anti-DEI bills or could be in the process of drafting them.

**What can be done?**

Companies with greater diversity are more likely to have higher financial returns. In order to foster this diversity and inclusion, practical steps include being a mentor, celebrating the achievements of individuals who may go unrecognized, volunteering, giving a seminar, building a team of diverse individuals, and checking your own biases.

Latinos are underrepresented in federal research funding, publications, speaking engagements, editorial boards, and leadership roles. One way to participate in the solution is to be an Upstander, not a Bystander. This means individuals must move beyond providing support in private, as bystanders, to responding to the perpetrator at times in public, as an upstander.

At the community, organizational, and policy level, interventions must include education for leaders and mentors; resources for navigating isolation, hypervisibility, stereotype threat, and institutional racism; and providing support for underrepresented-minority-specific local and national funding opportunities. Dr. Franco shared some initiatives that are already underway, including the intentional integration of a representative workforce in online educational materials, the Radiation Oncology Intensive Shadowing Experience (RISE), infographics for patient education on radiation oncology, and the Association of Residents in Radiation Oncology's (ARRO) Equity and Inclusion Subcommittee (EISC).

Dr. Franco ended by recommending action. Be intentional. Ask, “What voices are missing and how can we be more inclusive with our language and participation?” Foster a culture of community and belonging where differing identities are respected, individuals feel safe to bring their authentic selves, and people are empowered to reach their full potential. Build programs and interventions that optimize workforce representation and that are scalable, sustainable, and have a measurable impact. Finally, figure out what your privilege is, and use it to help others.

## Increasing the Number of Latino Oncologists and Strategies to Effectively Recruit Latino Oncologists

Dr. Gladys I. Rodriguez is a Medical Oncologist at the START Center for Cancer Care.

**Disparities in medical oncology**

Dr. Rodriguez began by discussing work done with colleagues at the American Society of Clinical Oncology (ASCO) in 2014 assessing the oncology workforce landscape. This work revealed that although 16.3% of the population at the time was Latino, only 7.4% of medical school graduates were Latino, and only 4.1% of medical oncology practicing physicians were Latino. In 2020, that representation had not improved, with Latino individuals representing 18% of the US population and only 3% of practicing oncologists. This discrepancy can be partially traced to the low number of Latino applicants to medical schools. In 2018-2019 only 6.2% of applicants were Latino, compared to 8.4% Black applicants, 21.3% Asian applicants, and 46.8% White applicants.

Underrepresentation in medical oncology has real-world consequences, with very little improvement in cancer deaths observed among Latino patients since 1990. This is in contrast to relatively large improvements for non-Hispanic Black and non-Hispanic White patients. In 2022, ASCO's Equity, Diversity, and Inclusion (EDI) program published a snapshot of the US medical oncology workforce, with a special focus on oncologists who identify as Hispanic or Latinx. Although only 4.7% of US oncologists are Latino, 9.3% of new cancer cases are in Latino patients. Furthermore, of these Latino oncologists, 22.0% are nearing retirement, while only 13.9% are 40 years of age or younger.

### ASCO's action plan

In order to combat the disparities in representation seen in medical oncology, ASCO's EDI program has formulated an action plan consisting of 3 steps. First, recruitment to clinical trials must more accurately represent the population of patients with cancer. Only 6% of participants in cancer clinical trials are Latino, a problem not seen in cardiovascular clinical trials. Next, the oncology workforce must better reflect the diversity of the population and be well equipped to deliver high quality care. Finally, barriers to accessing care must be decreased, and high quality, equitable care must be delivered to all patients with cancer.

ASCO's Oncology Talent and Diversity Programs are intended to build a diverse pipeline and longitudinal support for the oncology workforce. The Oncology Summer Internship, for example, is a 4-week immersive oncology program serving rising second year students from populations underrepresented in medicine at partnering medical schools to enhance exposure to the field of oncology. The Medical Student Rotation for Underrepresented Populations is another program providing financial support for US medical students from populations underrepresented in medicine. Recipients participate in a minimum 4-week clinical or clinical research rotation and are paired with a mentor who oversees the rotation and provides ongoing feedback and academic guidance.

Two additional programs include the Annual Meeting Research Award and the Diversity Mentoring Program. The Annual Meeting Research Award allows non-oncology physician residents from populations underrepresented in medicine who are interested in pursuing a career in oncology to attend the ASCO Annual Meeting. At the meeting, they present their research at the Abstract Forum, meet leading oncologists, and learn more about career options in the field. The Diversity Mentoring Program fosters relationships between mentees and mentors, who provide career and educational guidance virtually and serve as a professional resource. Career development webinars and virtual situational mentoring are also components of the program.

ASCO also provides Research Awards in Diversity, Inclusion and Health Disparities. These include Young Investigator Awards (YIA), Career Development Awards (CDA), Advanced Clinical Research Awards (ACRA), and Research Professorships in Diversity, Inclusion, and Health Disparities. A newer award, established by Dr. Rodriguez and colleagues in 2021, is the Women Who Conquered Cancer Latina Young Investigator Award. In 2023, the Robert A. Winn Diversity in Clinical Trials Program was established.

The American Association for Cancer Research (AACR) also provides awards for diversity, equity, and inclusion. These include AACR Career Development Awards to Further Diversity Equity and Inclusion in Cancer Research, the AACR Cancer Disparities Research Fellowship, and the Breast Cancer Research Foundation (BCRF-AACR) Career Development Award to Promote Diversity and Inclusion. These awards, along with the many provided by ASCO and others, make a positive difference in representation in the field of oncology. This increased representation can lessen the disparities experienced by Latino cancer patients.

## Task Force: Latino Researchers Against Cancer

*This session occurred at 11:15 a.m., Friday, Feb. 23, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

Dr. Amelie Ramirez is Professor at the University of Texas (UT) San Antonio, Director of the Institute for Health Promotion Research, Chair of the Department of Population Health Sciences at UT Health San Antonio, and Associate Director of Cancer Outreach and Engagement at Mays Cancer Center.

Dr. Ramirez's presentation focused on communicating the mission and first year results of the Task Force: Latino Researchers Against Cancer (TFLRAC). The Task Force's mission is to meet quarterly for 2 years to dialogue and identify critical issues and specific recommendations to address the burden of cancer in Latinos by providing insight and informing debate on current and emerging cancer issues impacting the Latino community. The Year 1 (2023-24) goal was to explore the causes and multilevel drivers of health impacting the Latino cancer experience. The Year 2 (2024-25) goal is to provide specific recommendations for interventions to address these causes based on scientific evidence to reduce the burden of cancer in US Latinos.

In Year 1, two overarching questions were considered: 1. Why do we think cancer has become the first cause of mortality among US Latinos? 2. How can we address the unique cultural, linguistic, and socio-economic barriers contributing to disparities in cancer incidence, mortality, and survivorship among US Latinos?

The Task Force identified 5 categories of factors affecting cancer in Latinos: factors directly causing cancer in Latinos, factors disproportionately affecting health in Latinos, factors affecting the understanding of cancer in Latinos, factors limiting support for Latino cancer patients, and factors affecting the entirety of the Latino cancer continuum.

Factors directly causing cancer in Latinos include environmental factors and genetic factors. Pollution, toxic waste, agriculture and construction job exposure, secondhand smoke, and other factors associated with climate change disproportionately affect Latino individuals. Genetic factors associated with heritage are also present, underlining the need for more research and more gene sequencing.

Examples of factors disproportionately affecting health in Latinos are cultural and linguistic factors, health behaviors, access to nutrition, and access to healthcare. The language barrier, combined with a lack of understanding of Familismo, Fatalismo, Machismo, and Marianismo can limit communication and connection between provider and patient. Low levels of health insurance coverage are also a major concern, with 18.3% of the US Latino population being uninsured.

Factors affecting the understanding of cancer in Latinos mainly involve clinical trial design and participation. Only 2.8% of participants in phase I clinical trials for anticancer agents are Latino. Furthermore, clinical trial design must account for Latino heterogeneity.

One factor limiting support for Latino cancer patients is a lack of prevention and early detection. Patient education, cancer screenings, and enrollment in insurance programs are best achieved at the community level, but the main barrier to this support is cost. Empowerment and resources are also lacking for Latino cancer patients. Finally, survivorship and end-of-life care for the Latino community is often overlooked.

Factors affecting the entirety of the Latino cancer continuum include policy and industry engagement and resources. Cancer centers and the Cancer Moonshot Program are a potential avenue for positive change, but policy can do more to empower Latino cancer patients through improved access to resources and support. The industry can also be a powerful agent of change through funding equitable clinical trials, advocacy, and education.

In Year 2, the Task Force plans to build on Year 1 results by formulating specific, evidence-based recommendations aimed at reducing the cancer burden in Latino communities. Critical areas include improving patient education, healthcare access, Latino participation in clinical trials, and advocacy for change. Beyond recommendations, the Task Force in Year 2 hopes to lay groundwork for practical implementation – through collaborative efforts among academia, healthcare, government, and industry – for real-world impact and a more equitable healthcare landscape for Latinos.

## Pharma Panel: Investing in Latinos' Health

*This session occurred at 11:30 a.m., Friday, Feb. 23, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

---

### Genentech

Dr. Veronica Sandoval is a Principal of Patient Inclusion and Health Equity in the Chief Diversity Office at Genentech.

In the realm of diversity and inclusion, Genentech is committed to being an industry leader by driving scientific innovations that enhance outcomes for its people, patients, business, and communities. Genentech's mission boldly champions diversity, equity, and inclusion.

The Advancing Inclusive Research (AIR) Site Alliance initiative aims to expand the participation of historically underrepresented groups in clinical research, ensuring all patients benefit fully from personalized healthcare solutions. The AIR Site Alliance demonstrates significant impact: Black and Latinx patients enroll two times faster than at other study sites. Additionally, the six AIR oncology sites achieve an 80% more diverse patient population compared to their study peers, while the three AIR ophthalmology sites achieve a 48% higher diversity. Genentech collaborates closely with the AIR Site Alliance sites to co-create educational resources, including patient and healthcare professional videos, to improve representation.

Genentech also sponsors community-based health equity symposia nationwide, focusing on healthcare disparities and local solutions to advance health equity. Initiatives like Fiesta Fairs and Univision Health Fairs provide vital services such as vision and cancer screenings and promote public health literacy among the Latino community, raising awareness about cancer and chronic disease risks.

### Bristol Myers Squibb

Dr. Constanza Kurman Petrozzelli is Co-Lead for the Health Equity Pillar in the Organization for Latino Achievement at Bristol Myers Squibb.

Bristol Myers Squibb (BMS) is addressing the need for greater diversity in clinical trials by taking a holistic approach. For the Organization for Latino Achievement (OLA) program, this begins with a better understanding of the needs of Latino patients, assessing healthcare provider behaviors, strengthening their presence in the community, outreach, and enrollment efforts. The OLA team partners with BMS's Diversity in Clinical Trials (DiCT) program to ensure the participation in clinical trials is more reflective of the real-world population and aligned with the epidemiology of the disease studied. This involves intentionality in site and investigator selection, protocol design considerations, communication and engagement, patient support, training, and metrics and measures.

Reaching for Equitable Access for Latinos (REAL) Workshops are one way to facilitate Latino participation in clinical trials. At the 2023 annual workshop, barriers and strategies to Latino participation were discussed. Strategies included prioritizing availability of consent forms translated in Spanish, expanding trial eligibility criteria to be more inclusive, providing nurse navigators to sites, simplifying the trial process to reduce administrative burden, and incorporating principle investigators serving diverse patients in the trial design process.

Despite efforts to increase Latino clinical trial participation, much of the research and corresponding action plans paint the community in broad strokes and fail to recognize the varying degrees to which ethnicity impacts the patient experience, ultimately causing the subconscious impact of ethnicity to be underrepresented. BMS has the potential to make a meaningful impact by helping with the established socioeconomic challenges, such as financial assistance with treatment and health education efforts, and specifically designing resources for the Latino community.

## Gilead

Dr. Jesse Garcia is the Bilingual Health Equity Strategist, Oncology and Virology Medical Scientist, and Certified Diversity, Equity, and Inclusion Professional at Gilead.

Gilead seeks to grow for greater impact by bringing transformative therapies to patients. It also aims to be the biotech employer and partner of choice and deliver shareholder value in a sustainable, responsible manner. Ambitions for this growth span three therapeutic areas. In virology, Gilead seeks to end the HIV epidemic; eliminate hepatitis C and advance options for hepatitis B and D; and continue reducing the burden of COVID-19. In oncology, through a partnership with Kite Pharma, Gilead’s goal is to change how cancer is treated through cell therapy, offering remission and potential for cures for many more people. This involves delivering transformative therapies in 20+ indications, impacting 500,000 patient lives, and being a top 10 oncology company by 2030. In inflammation, Gilead seeks to advance new treatments to help people living with a range of inflammatory and fibrotic diseases.

Beyond medicine, Gilead believes that their innovation will impact patients most when societal barriers to care are removed. In fact, the company’s global health equity priorities include helping to enable access to life-changing medicines, delivering scientific innovation to reduce inequities, and igniting social impact for the communities we serve. Gilead, which is the top global philanthropic funder of HIV causes, provided $260 million in funding to community organizations in 2022. Furthermore, Gilead has partnered with 127 low- and middle-income countries on access to medicines and building sustainable health systems and has committed $10 million to organizations fighting the racial inequities that affect communities of color.

## AstraZeneca

Kemi Williams, MBA is Senior Director of Patient Sciences in the Chief Medical Office at AstraZeneca.

AstraZeneca is committed to designing clinical programs with diversity at the forefront through data-driven continuous improvement, innovative solutions, and effective external partnerships. Because representation is critical from discovery to delivery, AstraZeneca is increasing the diversity of clinical trial participants so trials better reflect the patients who may use their medicines.

Project Ignite set out to identify the barriers and opportunities to improve participation of racial/ethnic minority patients in chronic kidney disease and breast cancer studies. After extensive global and national research, 6 insights were identified to guide future research across the company. First, successful research sites separate race and ethnicity from socioeconomic status and tailor support accordingly. Next, racial/ethnic minority barriers are similar across diseases, and sites that do well support patients according to their social determinants of health. Sites can also recruit faster when diversity has been considered in the study design and recruitment strategy. Racial/ethnic minority or low socioeconomic patients may require support that relies on site infrastructure and resources. Local sites are better positioned to lead the engagement based on community needs. Finally, local research sites can accelerate racial/ethnic minority recruitment with sponsors that consult the sites upfront on diversity.

One successful partnership to address disparities in care and clinical trials in historically marginalized populations like the Latino community has been the American Cancer Society (ACS) National Breast Cancer Roundtable (NBCRT). As part of the Cancer Moonshot program, objectives include strategic partnerships to eliminate disparities and reduce mortality, ensuring access to quality screening and treatment, and addressing social and emotional needs of patients and their families. AstraZeneca has been approached to become the industry sponsor of this program.

# AACR Special Session - Breaking Barriers: Progress and Challenges in Shaping the Future of Cancer Research, Care, and Policy for All Populations

*This session occurred at 8:15 a.m., Friday, Feb. 23, 2024, at the 4th biennial Advancing the Science of Cancer in Latinos conference.*

Drs. Amelie G. Ramirez, Mariana C. Stern, Ruben Mesa, Jon Retzlaff, and Rajarshi Sengupta

This panel discussion focused on the potential partnership between Advancing the Science of Cancer in Latinos (ASCL) and the American Association for Cancer Research (AACR). The AACR is committed to reducing cancer disparities and achieving health equity, partially through its Minorities in Cancer Research (MICR) initiative. MICR is committed to addressing cancer disparities in minorities and medically underserved populations and advancing the careers of minority scientists.

The AACR has been hosting the Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved since 2007. The AACR Cancer Disparities Progress Report Series is an initiative with the goal of educating members of Congress, the public, and the scientific community about cancer disparities and the importance of medical research for the elimination of disparities. This initiative also advocates for increased federal funding for health equity-focused research. Since 2019, the AACR has received $15.3 million in funding from 10 industry and foundation partners to support diversity, equity, and inclusion (DEI)-focused and disparities-focused research.

## Conclusion

To eliminate cancer disparities in Latinx populations, *Advancing the Science of Cancer in Latinos* brought together researchers, scientists, physicians, healthcare professionals, patient advocates, and students from across the US and Latin America. These presenters shared research advancements, identified gaps, developed actionable goals, updated clinical best practices, described effective community interventions, and detailed professional training programs aimed at addressing inequity. In the process, most of the speakers made recommendations, either specific to their field of study or more broadly. The following are some key recommendations abstracted from their conference presentations.

### Recommendations

#### Addressing Systemic Inequities Behind Cancer Disparities

**Access to prompt needed care is essential.** Latinx patients with excellent experiences in getting care quickly have greater odds of receiving stage-specific guideline-concordant cancer treatment. [Farias]

**Successful interventions should be adapted linguistically and culturally for a Latinx audience.** Each Latinx audience, and each Latin American country, has its own opportunities and challenges, and training local clinicians is essential. Collaborative efforts make sustainable solutions possible. Furthermore, successful adaptation of interventions is not merely about translation, but includes cultural adaptation as well. [Costas-Muñiz, Tamí-Maury]

**Language concordance between clinician and patient is vital to the Latinx cancer experience.** Language concordance offers many advantages, including improved quality of care, with patients that are less likely to feel confused and frustrated, and greater patient satisfaction. Likewise, health outcomes are positively affected, with improvements noted in glycemic control, medication adherence, and understanding of medication and dosage. Finally, relationship factors are impacted by language concordance, with greater agreement with physician recommendations, more questions asked by the patient, and greater disclosure of sensitive information. [Martinez]

**Toxicity in Latinx pediatric cancer patients should be reduced when possible.** Strategies for reducing toxicity may include the following approaches: therapy reduction, including reduction of exposure duration, cumulative dosing caps, and risk-adapted therapy plans; the use of less toxic drugs including immunotherapy and CAR-T; the use of pharmacogenomics to drive drug dosing decisions; and increasing the number of supportive care trials. [Grimes]

**Technology may be vital for patient education and engagement.** Text messaging- and app-based systems have been used to remind and educate AYA survivors, improve the no-show rate for colonoscopies, and facilitate smoking cessation. Digital health solutions can also improve access to care, increase efficiency, and reduce costs for smoking prevention and control. Machine learning-based tools have proven useful in prediction of gastric cancer incidence using endoscopic and histologic features. Artificial intelligence can also be useful in diagnosis, prognosis, and staging; in the identification of pathology slides; in recommender systems to help patients navigate issues that are important to them; and through the use of natural language processing to improve patient-clinician interactions. [Casillas, Camargo, Cupertino, Piette, Hernandez-Barco, Chalela, Tamí-Maury]

**Food programs are integral to the reduction of food insecurity.** Federal food programs for mixed age groups include grocery programs such as food bank-operated pantry programs, ad hoc food pantries, home-delivered groceries, mobile markets and pantries, school or other pantries, and community gardens. Food pantry programs should emphasize food equity, meaning client choice is prioritized and a nutrition-based food selection system is utilized. Less food insecurity and healthier food are associated with lower colorectal cancer incidence and mortality. [Pruitt, Serra]

**Young Latina mothers diagnosed with cancer need extra help.** Medical assistance is needed for symptom management, including preparing Latinas on what to expect and strategies for managing extreme side effects. There is also a need for training and recruiting pain management and behavioral health specialists to underserved regions such as the border region, where there are high numbers of young Latina mothers diagnosed with cancer. Culturally adapted cancer parenting programs can help address disparities in social determinants of health. [Palacios]

## Cancer Screening Disparities

**Access to genetic counseling and testing must be expanded.** The scarcity of Spanish-speaking genetic counselors may be overcome through alternative delivery models such as genetic counselor extenders (e.g. group counseling), telephone genetic counseling, patient-facing materials such as brochures and websites, or educational videos. Polygenic risk scores, often formulated based on European populations, may be adapted for use in predicting the risk of certain Latinx cancers. [Hurtado de Mendoza, Fejerman, Serra]

**Prevention and screening programs are vital.** Age-appropriate cancer screenings should be an emphasis for intervention, and should be nimble, incorporate more long-term disaster planning approaches, and use telehealth and improved data tracking tools. Clear policies and access to vaccination and antivirals should also be prioritized for all cancer patients. [Hernandez-Barco, Coronado, Vilar-Compte]

## Latinx Cancer Research Methodology

**Community engagement is needed to build trust for sustainable relationships.** Research must be initiated in full partnership with community members, scientists, and the government. Scientists must listen to the concerns and problems of the community and decide on a research plan together. The research plan must be sustainable over time, have shared governance, provide tangible financial support, and include a partnership based on trust, mutual benefits, complementary skills, and a focus on health. One example of an NIH program working to build trustworthy partnerships is the Community Engagement Alliance (CEAL). [Perez-Stable]

**Standardized measurements and questions are needed to ensure Latinos are not underrepresented.** There is a need for validated instruments in the context of Latinx cancer clinical work and research in order to standardize Latinx identification and measure social determinants of health. One solution to the need for standardization of information across scientific studies is the use of the PhenX Toolkit to measure social determinants of health, developed in 2022. [Perez-Stable, Costas-Muñiz]

**Appropriate data is needed to facilitate discovery science.** Because the Latino population is overall younger than the national average, age-adjusted death rate (AADR) is a useful tool in facilitating accurate cancer mortality data. Clinical trials in Latin America are needed to convince governments to spend money on proven cancer treatments, and to shed light on Latino cancer in the US. Limiting clinical trial data collection in late phase trials to essential data elements may allow for greater efficiency and lower cost. Finally,  multi-omics approaches can provide insight into cancer disparities research. [Perez-Stable, Sáenz, Cabrera, Doroshow, Velazquez]

**Electronic health records (EHRs) may be used to support clinical trials.** Clinical trials may be improved by vendors creating mechanisms for automatically integrating study-specific documents into local implementations of their products, and resolving the logistical and data quality challenges of extracting clinical trial data from electronic health records. [Doroshow]

**Clinical trial workforce issues must be addressed.** This can be accomplished by streamlining and standardizing trial activation processes, reducing the volume of trials staff are responsible for, increasing flexibility for remote work, improving alignment of institution and cancer center hiring processes related to staff recruitment and retention, and using a virtual clinical trials office. Furthermore, diversity of the scientific and clinical workforce should be promoted. [Perez-Stable, Doroshow]

### Latinx Clinical Trial Participation

**Approaches to improve enrollment must be tailored to specific settings, and should address structural barriers to Latinx participation.** This is in addition to ensuring that demographics of patients enrolled in clinical trials are comparable to the US population. Trials must intentionally recruit in Latino-dense regions, and include public health and clinical collaboration leading to Spanish consent forms and culturally adapted recruitment and study materials. Structural barriers for Latino participation should be considered during study design and informed consent design. Paying community organizations to get involved could be an effective approach. [Aristizabal, Palacios, Rios, Adjei]

**Provider-level training focused on patient-provider communication is important.** Linguistically appropriate tools and culturally-aware staff are vital to clinical trial enrollment. [Aristizabal, Adjei]

**Patient-level factors are key.** These factors include building trust; education and awareness of clinical trials; culture, language, and health literacy-focused interventions; and initiatives to address socio-economic barriers. [Aristizabal, Adjei]

### Latinx Cancer Survivorship

**More research is needed in the area of Latinx cancer survivorship.** First, the disaggregation of Latinx cancer survivorship data is imperative to fully understand outcomes among different groups of Latinx survivors. Evidence-based strategies must be adapted to reduce disparities in symptom burden, and investment must be made in cancer survivorship research, community partnerships, training, and diversifying the cancer survivorship research and clinical workforce. [Graves]

**Effective patient-provider communication is central to timely, targeted integration of palliative care.** The preferred approach to palliative care is patient-centered with a needs-based approach, systematically identifying patients who are likely to benefit from palliative care through screening, deploying care in response to their symptoms and supportive care needs, and proactively avoiding symptom crises and improving quality of life. [Moreno]

**Latinx adolescent and young adult (AYA) survivorship needs must be considered.** In light of disparities in survivorship for some AYA cancers such as leukemia, AYA-specific interventions are needed: cancer prevention and health promotion counseling must be provided for risk reduction, screening must be prioritized for early detection of late effects, hereditary genetic predispositions and appropriate genetic counseling should also be considered, and assessment of cultural beliefs, environment, and inclusion of Latinx participants in research should be prioritized in order to develop interventions to achieve health equity in cancer survivorship care. [Casillas]

**Exercise programs can be effective for survivors.** Such programs can reduce metabolic syndrome in sedentary, overweight or obese breast cancer survivors, and high-intensity interval training programs are associated with significant improvements in cardiometabolic, physical, and psychosocial health outcomes among sedentary, overweight or obese breast cancer patients. [Dieli-Conwright]

**Self-acupressure may be a useful tool in symptom management.** The stimulation of acupoints triggers the hypothalamic-pituitary-adrenocortical axis in order to influence sympathetic and peripheral nervous system function. It can also be performed at home for no monetary cost. [Graves]

## Further Resources

**The Division of Cancer Control and Population Sciences (DCCPS)** seeks to expand and enhance research to understand and mitigate the impacts of the environment and climate change on cancer across the care continuum. [Ellison]

**The Formación de Investigacion Psicosocial Oncológica Latinoamenricana (FIPOL)** was founded to connect clinicians, educators, and researchers from Latin America and Spanish-speaking countries interested in psychosocial oncology, behavioral medicine, and palliative care. [Costas-Muñiz]

**The National Association of Medical Spanish** was formed to build a pipeline of Spanish-speaking providers to address cancer in Latinos. [Martinez]

**The Physician Oral Language Observation Matrix (POLOM)** is a rater-based tool for assessment of medical oral language skills as contextualized for patient care. This matrix provides a way to reliably evaluate whether a physician is ready to perform their patient care responsibilities in a non-English language. [Martinez]

**The ÁRBOLES Familiares Training Program** seeks to address disparities in awareness and uptake of genetic risk assessment among Latinos. [Graves]

**COMPRENDO (ChildhOod Malignancy Peer REsearch NavigatiOn)** is a peer-navigation intervention to improve research literacy and diversity in pediatric cancer clinical trials. In the program, peer-navigators provide in-hospital support, telephone support, and in-home support. [Aristizabal]

**The Persistent Poverty Initiative (PPI)** aims to address structural and institutional factors to alleviate the cumulative effects of poverty on cancer outcomes by building research capacity, fostering cancer prevention research, and partnering with communities to promote the implementation of community-based programs. [Srinivasan]

**The National Hispanic Medical Association (NHMA)** is a nonprofit started in 1994 with the mission of empowering Latino physicians and Latino-serving physicians to improve the health of Latinos. [Rios]

**The All of Us Research Program** is a historic, longitudinal effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, socioeconomics, environment, and biology, the hope is that researchers will one day uncover paths toward delivering precision medicine – or individualized prevention, treatment, and care – for all of us. The All of Us Research Program is part of the broader Precision Medicine Initiative. [Mendoza]