

Chapter 21

Emerging Policies in US Health Care



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Many of the issues discussed at the conference, such as testing, clinical product rules, drug approvals, and funding for research, clearly touch the arena of public policy. At the close of the conference, Dr. Ruben Mesa, Director of the Mays Cancer Center at UT Health San Antonio, chaired a panel discussion on emerging policies in US health care. The diverse, expert panel offered different perspectives on emerging health policy. The panel included:

- Congressman Joaquin Castro, Representative from the 20th Congressional District in Bexar County, Texas
- Dr. Esteban López, Chief Medical Officer, Clinical Strategy and Innovation at Blue Cross and Blue Shield of Texas
- Dr. Robert Croyle, Director, Division of Cancer Control and Population Sciences at the National Cancer Institute
- Dr. Elena Rios, President and CEO of the National Hispanic Medical Association

Congressman Joaquin Castro, Representative from the 20th Congressional District in Bexar County, Texas

Congressman Castro began the session by stating that cancer and heart disease are the two diseases that claim the most lives of Latino Americans. In Texas, that problem is especially pernicious. Congressman Castro pointed out that he is very much

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involved in public policy that supports the research that many of the researchers at the conference are doing—research that will help save the lives, not only of many Latinos, but of all Americans. His main message to researchers was to advocate for their own work and educate policy makers in Congress of its value in helping people and saving lives. In doing so, he suggested that researchers should be persistent because lawmakers are juggling many issues in addition to healthcare and may need reminding to refocus their attention. He reminded the audience that there was an infusion of new money earmarked for cancer research, with Vice President Biden’s MoonShot Initiative funded through the 21st Century Cures Act, but warned that National Cancer Institute would still need to cut their operating budget and deal with increasing requests for research funding. Congressman Castro has been speaking out about the need to increase funding for cancer research and not back away from that commitment.

Ruben Mesa, Director, Mays Cancer Center at UT Health San Antonio asked, *“What opportunities are there for being the voice in getting important policies implemented related to issues regarding cancer in Latinos?”*

Congressman Castro responded that there is an incredible opportunity for researchers and community leaders and many members of Congress and state legislatures to make an impact in funding and policies passed by legislative bodies. For example, the Tri-Caucus, which comprises the Congressional Asian Pacific American Caucus (CAPAC), the Congressional Black Caucus (CBC), and the Congressional Hispanic Caucus (CHC), led legislation efforts in previous years that would improve cancer funding and cancer research among minority groups. But that legislation did not move in Congress the way it was expected. Therefore, there is a great need for advocates to come to Washington and make the case that this is important work.

We must also protect the Affordable Care Act because one part of it, the individual mandate, has been recently removed. Latinos were the biggest beneficiaries of the Affordable Care Act; more Latinos than any other group were able to receive insurance coverage because of that act, so researchers and community members must make sure that it is not eroded any more. One other important issue that must be addressed is the environmental quality of many Latino communities. This is deeply challenging in places like Texas. For example, the environmental agency that regulates companies in Texas is the Texas Commission on Environmental Quality (TCEQ). It is charged with enforcing air, water, and waste management violations. Over a multi-year period, the state agency found only a fraction of the air and water violations from different polluters. As a consequence, there are huge Latino communities that are exposed to damaging environmental factors because of weak enforcement in certain states like Texas. This is important when one considers the health effects of the environment on cancer and other illnesses. Thus, everyone must be mindful, not only of Congress and the federal government, but also of state and local jurisdictions.

Dr. Esteban López, Chief Medical Officer, Clinical Strategy and Innovation at Blue Cross and Blue Shield of Texas

Dr. Lopez spoke about Understanding Drivers and Barriers for Latinos in Cancer Care; he began by addressing the difference between “Equal and Equitable.” While physicians may try to treat patients in an equal manner and offer equal care, equal care is not necessarily equitable, because patients face different challenges to receive the care that they need. Blue Cross wants to not only give patients access to care but also address social indicators of health that prevent patients from receiving their highest potential level of care.

Addressing cancer disparities among Latinos first requires knowledge about what health challenges Latinos face. In addition to using published research, Blue Cross is using online research to see how Latinos are communicating online. Blue Cross partnered with a vendor who mines and structures qualitative data; examines who is talking, where users are talking and what they are talking about in reference to cancer; and determines underlying drivers and barriers. Blue Cross wants to know what the barriers and attitudes are, so they can understand in real time what their Latino members are experiencing. Using breast cancer as an example, he described the following strategies for offering culturally relevant care:

- *There is a crucial need for early detection.* Breast cancer is the most common cancer in Hispanic women. As a population, Hispanic women are reactive to care; they seek medical care when they are sick but do not necessarily go to a physician to seek preventative care. To encourage proactive screening, there is a need to go where they are, such as their places of business, with mobile mammography; and we must find other methods to ensure screening as we continue to educate the Latino population.
- *Respect cultural differences.* Latinos online show less knowledge about breast cancer and express the competing priorities of job and family in relation to getting mammograms. In terms of Latino care, we must include the whole concept of family and community. We have a call to action to design dedicated strategies, interventions, and activations that tackle the specific unmet needs and cultural nuances of Hispanic breast cancer patients and their caregivers.
- *Target both patients and caregivers, including male caregivers.* Latinos tend to be collectivistic, so the caregivers are influential in the lives of patients with cancer. The goal is to create a two-pronged approach that involves and educates the caregiver as well as the patient.
- *Target primary care physicians.* Primary care physicians (PCPs) can be the number one driver or barrier for proper cancer care and adherence to treatment. Latinos tend to be deferential to their physician and may not question a treatment that will be given. Because a small percentage of physicians are Latinos, we must empower non-Latino physician partners with cultural competence to enhance their relationship with breast cancer patients and their caregivers.

- *Foster advocacy within the community.* Data from social media and chat rooms show that while there are many conversations happening online, there is a lack of advocacy for Latino cancer survivors. There is a need to involve Latino cancer survivors in advocacy, sharing the issues they faced. The powerful voice of survivors can be leveraged to motivate women to seek breast cancer screening.
- *Leverage online channels.* Many Latinos actively use social media and smart phones, and they go to online communities for information about cancer care. So, health care systems must give out information where Latinos are going first. We must also look beyond Facebook and Twitter to online chat communities and message boards. Because the Internet is a powerful channel for Hispanics to find information and support, there is a call to action to think holistically and include online as another channel along the path to treatment.
- *Protect patients through local policy.* Physicians, health care systems and insurance companies must step up to advocate for the communities they serve. For example, Blue Cross and Blue Shield of Texas helped to raise the minimum age to buy tobacco to 21 in Bexar County and San Antonio. While the Latino health care population is younger and often has good health habits, once Latinos are treated for a chronic condition, unfortunately they often experience higher incidence of complication and death. And so, advocacy is important.

Dr. Robert Croyle, Director, Division of Cancer Control and Population Sciences at the National Cancer Institute

The field of health disparities research is evolving. Ten years ago, much of the disparity research was pigeon-holed into work on documenting gaps in access to care. It was important to document, understand, and explain health disparities, but the next generation of health disparity researchers is now focusing on disparities across the board, regardless of which community is being studied. That is, the science has moved from documenting what is wrong to raising aspirations and goals to what is possible. What is really compelling and exciting about this meeting is how much solution-focused research is now being done including interventions that are working, risk reductions that are happening, solutions around the uninsured and distance to care, use of technology, culturally appropriate care, building bridges between specialty and oncology care and primary care, and the expansion of navigation.

At NCI we need feedback, criticism, and honest talk. We need to know about many of the great innovations that occur at the local level in your communities, so that we can scale them up at a national level. So, in terms of raising our aspirations, one of the ways we do that is through the tremendous research infrastructure that the NCI supports along with NIH. This depends upon an adequate budget, and so at NCI, we feel fortunate because we have been told that the very last bipartisan area of agreement on the Hill is NIH. One of the ways we try to raise the bar across the whole span of basic, clinical, and population research in cancer is recognizing that

all domains of this research need to be revolutionized to better inform Latino health. At this meeting, we heard about basic science and the acquisition of biospecimens, genomics, molecular epidemiology, and the need for the representation of biological specimens from all communities—without which you can make erroneous inferences and conclusions.

Clinical research still has a long way to go in terms of underrepresentation of Latinos in cancer clinical trials. One of the barriers to Latino accrual is the use of comorbidities, such as hypertension and obesity, as exclusion criteria for enrollment in clinical trials. So, one question we are asking in our clinical research community and the NCI is: Are all these exclusion criteria really necessary in terms of eligibility to clinical trial enrollment? Some of these exclusion criteria are not even necessarily evidence-based. Researchers are being very cautious, trying to understand and reduce toxicity and side effects. But if you are excluding a very large proportion of our population for not a very thorough and sound evidence-based reason, we need to revisit it.

NCI has a large research infrastructure; we are proud of the 69 NCI-designated cancer centers around the country, but they do not reach all parts of the country yet. As a federal agency that funds grants, NCI has been raising the criteria, expectations, and standards to fund these cancer centers over the past several years. For example, community outreach engagement in our cancer centers is a requirement that has been enhanced in our funding guidelines. That has had a great spillover effect; many cancer centers now have associate directors of community outreach engagement. NCI will continue this strategy by adjusting criteria every year. More recently, NCI asked cancer centers to clearly define their population catchment area. Have some ownership, have some engagement, and describe who you think you are serving in your community. It is no longer acceptable for cancer centers to say, “these are the people in trials, because these are the people who can afford to travel, who can come to our center and stay here in a hotel for a week.” So NCI has raised the bar in expectations and provided the additional money to do that. It is one thing to change the rules, but we want to avoid unfunded mandates as well.

Another important role that NCI plays is through its cancer registry systems, which have been discussed throughout the conference. The way NCI tries to validate its cancer statistics is by branching cancer registry data and linking it to census data. The census is where people self-report their race and ethnicity, so it is viewed as the gold standard. Data linkage is really of key importance, and without a good census, we cannot track progress in cancer at a national level. The census is not only the key denominator to cancer but also for other diseases that reach across the country. So we are proud of our cancer registry system, our surveillance system in the United States. This is our national report card. We are going to be finishing our next annual report on the nature of cancer shortly, focusing on prostate cancer. This is a data quality issue, so if you want to support cancer research, support a good census. And that means not including elements that deter people from participating.

Finally, there is the issue of cultural competence of non-Latino physicians in Latino communities. One of the most common complaints we still receive from cancer patients is poor communication. “I don’t understand my treatment.” “I don’t

understand the diagnosis.” “I don’t understand the prospects for recurrence.” “What’s going to happen to me next?” “What are my side effects?” In response to this, NCI has been trying to contribute to a solution in a small way by translating the patient-reported outcome system we use for clinical trials into 14 different languages. So the measures we use in our research have to be available in Spanish language and must be carefully done and carefully validated.

Dr. Elena Rios, President and CEO of the National Hispanic Medical Association

Dr. Rios spoke about cancer and Hispanic Advocacy. There are two important trends from current health policy issues that impact all of us. The first is that the size of the Latino population is growing; in 2015, 1 in 5 people in the United States were Hispanic, and by 2045, the ratio is projected to be 1 in 4 [1]. This growing demographic has the potential to use the power of the vote to shape public policy. The second trend is that the uninsured rate for Hispanics declined significantly after the Affordable Care Act (ACA)—the most transformative law in healthcare policy since Medicare for the elderly and Medicaid for the poor. The ACA gave Hispanic communities access to doctors, clinics, and hospitals with less financial burden, because insurance pays not only for medical and hospital care, but also medications. However, even though Hispanics have gained the most in terms of having more insurance, they still face many disparities. Thus, health care policy, for Hispanics, is important.

Congressional Legislation in the 115th Congress (January 3, 2017 to January 3, 2019)

The National Hispanic Medical Association is interested in advocacy; it is co-chair for the National Hispanic Leadership Agenda that includes the top 40 Hispanic organizations in the country, and it works with other coalitions for minority health. Some of the most important issues that need advocacy include:

Health Insurance Reform The Affordable Care Act (ACA) is the law of the land. Even though the individual mandate has been taken away, there are still essential benefits, consumer protections, and state marketplaces where competition drives the prices down. An important advocate, the Congressional Tri-Caucus, has influenced health care policy by promoting the need to address disparities in health care among minorities; they have introduced legislation every year for the last decade and have supported major parts of the ACA.

Research The 21st Century Cures Act provides funding to the FDA and NIH for expediting the development and delivery of new medical advances to patients who have hard to treat diseases such as cancer and Alzheimer's. The NIH earmarked funding from this bill for a program known as All of Us, which includes three initiatives—Beau Biden Cancer Moonshot Initiative, Brain Initiative, and Precision Medicine Initiative. The intent is to involve a diverse cohort of one million volunteers to provide personal health data and biological specimens for research. The NHMA is a national partner with the All of Us Research program and is interested in finding ways to involve the next generation of doctors in sharing the idea that more patients should become involved in clinical trials. Finally, there is the second study period of the Study of Latinos—a large NIH community-based, longitudinal, cohort study of Hispanics/Latinos in the United States.

CDC Cancer Prevention Programs Advocacy groups and coalitions, such as One Voice Against Cancer (OVAC), actively lobby Congress to appropriate funds to the Centers for Disease Control to conduct or support cancer research. The CDC Division of Cancer Prevention and Control has many cancer prevention programs that offer grant money including National Comprehensive Cancer Control Program, National Program of Cancer Registries, National Breast and Cervical Cancer Early Detection Program, Colorectal Cancer Control Program, National Skin cancer Prevention Education Program, Prostate Cancer awareness Campaign, Ovarian Cancer Control Initiative, Gynecologic Cancer and education and Awareness (Johanna's Law), and Cancer Survivorship Resource Center.

Health Workforce Programs: HRSA and Department of Education Health workforce programs of the Health Resources and Services Administration (HRSA) and Department of Education include funding for diversity recruitment and training, faculty development, and scholarships. On the House side, the Health and Education Workforce agreed with NHMA Summit recommendations for President Obama's STEM initiative, a major goal of which is to increase the diversity of underrepresented groups within science, technology, and mathematics. Also, it is time for reauthorization of the Higher Education Act (HEA). The NHMA has worked for years with Congressional offices to reauthorize HEA, which is a federal aid program administered by the Department of Education that supports students seeking post-secondary education. The hope is that there will be more opportunities for students in high school and college to become students for medical, nursing and dental schools, or to become STEM researchers of the future. Congressmen Raul Ruiz (D-CA) and Ruben Hinojosa (D-TX) have introduced bills to give more flexibility to Hispanic-serving institutions so that they may use their HEA grant funds for mentoring and advising students to enroll in medical and graduate programs that prepare students for health care occupations. As a result, more Hispanic students may enter the pipeline for health care professions, because their eyes will be open to the opportunity.

Minority Health: HEAA 2018 in Progress A large coalition has formed around Minority Health that is broader in scope than ethnic minorities; it also includes the disabled, women's health, and the LGBT communities. They are all working on a bill with the Tri-Caucus, which is called the Health Equity and Education Act (HEAA). This comprehensive bill aims to improve the quality of health care and eliminate disparities. It will address culturally and linguistically appropriate and value-based health care, as well as promote research and data collection on health needs and outcomes in diverse communities.

Health Policy Trends

There is polarization in Congress with more people at the extremes, so we must find a way to bridge the gap in order to make progress in addressing health care issues and disparities. For example, Democrats are promoting Medicare for All, a universal health insurance that is paid for with taxes; Republicans are proposing block grants, a set amount of money given to states to administer Medicaid that would not be responsive to changes in demand. However, there is bipartisan support for some insurance reforms such as reinsurance programs and subsidies including cost-saving reductions (CSRs) that enable insurance companies to help the poor, lower income and middle class in the United States. A new low premium/high deductible insurance product, the copper plan, is being proposed to offer more affordable insurance. There is also bipartisan support for Medicare Advantage, which is now 30% of the Medicare population. It was designed originally to offer a comprehensive insurance product with medication coverage before Part D was available.

Another health policy trend at both the federal and state level is the recognition that where people are located and the conditions in which they live influences their health risks and outcomes. Thus, there is a focus on social determinants of health such as poverty and income, housing, food security, transportation, financial literacy, education, employment, behavioral health, homelessness, and being in or having been in prison. In Massachusetts, which has been the leader in health reform and health insurance, measures of the social determinants of health are now being incorporated into research, state programs, Medicaid, Medicare, and the marketplace.

Health Care Trends: Medicaid

Medicaid is now the largest insurance with a new focus on flexibility at a state level. There is a push from the Trump administration to allow states to impose work requirements on Medicaid recipients. Ostensibly, the intent is to make recipients lead healthier, more productive lives. This is not the first time that work require-

ments have been part of policy. At the end of the Clinton administration, work requirements were imposed during welfare reform as an incentive to find jobs. One caveat is that there is no money allocated for child care or transportation.

States are experimenting with other ways to improve health and contain costs. For example, some states want to require Medicaid recipients to pay premiums and contribute to health savings accounts. If recipients are too poor to make these payments or do not understand the logistics, they risk losing coverage. To lower drug costs, some states are trying to negotiate value-based purchasing agreements with drug manufacturers. Some states are requesting waivers to allow providers to require participation in wellness programs, and some are allowing Medicaid recipients to use telehealth and telemedicine services so that they can receive medical care at home, giving access to health care for people who lack transportation or who are isolated in rural areas. There is also a move to improve outreach and to measure social determinants of health to inform health management policy and better serve the needs of low-income Americans.

Care Management Trends

When we started managed care in this country in the 1970s, it consisted of just administration of benefits and financing. Then we moved into an era of provider care management, where the emphasis was on the supply side to keep costs down and included measures such as utilization review, risk contracting, diagnostic-related groupings (DRG), and pay for performance (P4P). Now providers are using mainly consumer care management, which emphasizes the demand side, viewing patients as consumers who have choices. It focuses on how to change consumer behavior, for example, to visit the doctor and practice healthy behavior to prevent disease. The strategies for consumer care management are based on factors such as consumer centric behavior, work–life balance, population management, and outcome data. Community care management is a future model of care management that is gaining interest, primarily from Medicaid. This model moves the focus beyond the individual consumer to the community; the intent is to provide accountable, coordinated, whole-person care that will involve not only hospitals and clinics but also home care and caregivers. There will be a shift from hospital-based care to residence-centered care with decreased hospital stays and readmissions. Community budgets will be established for the target population with shared risk strategies between providers and the community, and there will be a shift from volume to value of care received.

Federal Strategic Plans

Some of the federal strategic plans are trendsetters for policies and are thus important to understand; a few of the more influential ones are mentioned here. The strategic plan from the US Department of Health and Human Services (HHS) focuses on high-risk populations now. In the new plan, the words diversity and disparities have been minimized; Latinos are still considered high risk, but are just not named. Another point of note is that every section of the new HHS strategic plan mentions giving more funding to religious and faith-based organizations, so researchers seeking funding might consider partnering with these groups.

The HHS Office of Minority Health (OMH) has a National Plan to Eliminate Disparities and has continued to support the National Partnership for Action (NPA). The OMH also has a history of support for the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care to be adopted by hospitals and leaders of our institutions and communities. Since 2003, the Agency for Healthcare Research and Quality (AHRQ) has put out an annual National Healthcare Quality and Disparities Report. This assessment of the US healthcare system points out the strengths, weaknesses, and disparities that exist in both quality and access to care. In 1999, the Institute of Medicine (IOM) was asked by Congress to examine health care disparities in the United States. In 2002, the IOM published *Unequal Treatment*, an influential report that was the first to document widespread health inequities in the United States and to map out general strategies for how to address them, including increasing awareness among the public, policy-makers, and health care industry and promoting evidence-based medicine to insure consistent, equitable care.

Finally, two other reports that have had important impacts on policy are *Healthy People* and the Report of the Lung Cancer Progress Review Group. *Healthy People* is a federal strategic plan that focuses on disease prevention; it is updated every 10 years and is administered by the Office of Disease Prevention and Health Promotion (ODPHP) at HHS. *Healthy People 2020* aims to:

1. Identify nationwide health improvement priorities
2. Increase public awareness and understanding of the determinants of health, disease, and disability and the opportunities for progress
3. Provide measurable objectives and goals that are applicable at the national, state, and local levels
4. Engage multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge
5. Identify critical research, evaluation, and data collection needs. (<https://www.healthypeople.gov/2020/About-Healthy-People>)

Published by NCI in 2001, the Report of the Lung Cancer Progress Review Group presented a vision for cancer research that is more multidisciplinary. Its “highest priority” was to foster the creation of integrated, multidisciplinary, multi-institutional

research consortia organized around the problem of lung cancer rather than around specific research disciplines.

Future: Cancer and Hispanics

Looking to the future for cancer and Hispanics, the National Hispanic Medical Association sees the need to educate policymakers. Each year NHMA has a national conference in Washington DC which includes a Lobby Day and a session for doctors, medical students, and others to stress the importance of not only cancer but also chronic disease in general in our communities and the need for more doctors. There are many issues discussed, but it is always about access for Hispanic communities, cultural competence, research, and whatever else we can do to help. We also work with coalitions such as the Tri-Caucus, Healthy Equity and Education Workgroup, Medicaid coalitions, Better Medicare Alliance, PhRMA Advisory Council, Public Health Institute new community-based coalition, National Hispanic Health Agenda, Children's Health Group, Immigrant Children Committee (AAP), and Health Professionals/Nursing Education Coalitions (AAMC). Finally, the NHMA supports Political Action Committees such as Hispanic Congressmen (GoBold), Poder PAC—Latina Congresswomen, and the Victory Fund started by Eva Longoria. It is not necessary to have much money to help political action committees, because Congressmen have their own mechanisms for generating funds which can be directed toward future Congressmen that will champion for cancer research. One recommendation for the future is to start a PAC that is just about healthy living in general, not just for Hispanics, but for everyone.

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Reference

1. Table 10. Projections of the population by sex, Hispanic origin, and race for the United States: 2015 to 2060 (NP2014-T10). Source: U.S. Census Bureau, Population Division. Release Date: December 2014.

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