NATIONAL HISPANIC PATIENT-CENTERED RESEARCH AGENDA
SUMMARY REPORT AND RECOMMENDATIONS

SUBMITTED TO THE

PATIENT CENTERED OUTCOMES RESEARCH INSTITUTE

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INTRODUCTION

The National Hispanic Health Foundation (NHHF), founded by the National Hispanic Medical Association (NHMA), has a mission to improve the health of Hispanics and other underserved communities. As the nation continues to implement health reform, there is an urgent need to increase the representation of Hispanic patients, caregivers, clinicians, and researchers in health services research, particularly utilizing a patient-centered approach.

NHHF proposed to facilitate the expansion of patient-centered outcomes research (PCOR) by

1) Developing a Hispanic patient-centered research agenda,
2) Building the skill and capacity of Hispanic-serving physicians, researchers, and Hispanic patients/consumers to conduct patient-centered research, and
3) Influencing Hispanic-focused health researchers to utilize more patient-centered approaches in their research.

This project included a PCOR Research Agenda Setting Session at the NHMA 21st Annual Conference on April 24, 2016 and a two-day PCOR Research Agenda Setting and Collaborative Planning Meeting June 28-29, 2016. A key project collaborator was the New York Academy of Medicine’s Center for Health Innovation.

NHHF accomplished the project outputs including: development of a multi-stakeholder steering committee to plan project activities; hosting the Hispanic Patient-Centered Research Booth at NHMA’s annual conference; facilitating the Hispanic PCOR Agenda Session at NHMA’s annual conference; gathering of panels of patients, researchers, and clinicians to discuss lessons learned on Hispanic PCOR and PCOR training and assess capacity building needs; networking opportunities to facilitate partnership development and cohesion; and facilitating the Hispanic Research Agenda Setting and Collaborative Planning Meeting; and the completion of a Final Report and wide dissemination.

I would like to thank the outstanding Hispanic researchers who were asked to be the steering committee members and speakers at the meetings and the patients from Mary’s Center in Washington, DC who were participants in research, Dr. Jose Pagan of the New York Academy of Medicine, consultant on the project, and the participants and staff at both meetings for their time in sharing their experience and discussing their guidance for future PCOR for Hispanic health research. Lastly, we thank the staff and Board of Directors for their vision to work with NHHF and develop the core knowledge to advance the health status of all Americans. This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award, (NHHF Hispanic Patient-Centered Research Agenda EAIN-3046).

Elena Rios, MD, MSPH
President, National Hispanic Health Foundation

NATIONAL HISPANIC HEALTH FOUNDATION
1216 FIFTH AVENUE, ROOM 457
NEW YORK, NY 10029
PHONE: 212-419-3686
WEBSITE: WWW.NHMAFOUNDATION.ORG
Hispanic PCOR Agenda Setting Meeting Summary
April 24, 2016

OPENING REMARKS
José Pagan, PhD
Director, Center for Health Innovation,
New York Academy of Medicine

It's very exciting to have this meeting that is going to be about not only how to increase Hispanic patients-centered outcomes research, but also how to increase the number of Hispanic researchers interested in working in this space. So what we have planned for you today is basically to have our keynote speaker in a second, which I will introduce, and have four presentations from our esteemed colleagues that do work in this space in different areas that range from cardiovascular disease to diabetes to cancer and so on. And then what we'll do is we'll break up into working groups to answer a couple of questions. One is what are the gaps that we see that are connected to Hispanic patient-centered outcomes research and the other is how do we get more Hispanic physicians interested in being in this space.

So let me introduce our keynote speaker, Alicia Fernandez who is a professor of clinical medicine at UC San Francisco and an attending physician in the general medical clinic and the medical ward at San Francisco General Hospital. Dr. Fernandez’s research focuses on health and health care disparities, and she is particularly interested in diabetes, Latino health, immigrant health, and language barriers. In addition to her research and clinical practice in San Francisco General Hospital, she's an active mentor of students, residents, fellows, and faculty. She has received several honors and awards, including the Arnold Gold Professorship for humanism in medicine. She has served as an advisor to the Raul Johnson Foundation, the California Endowment, NQF, Commonwealth Fund, and the American Medical Association. Most recently, Dr. Fernandez was appointed to the board of governors of the Patient-Centered Outcomes Research Institute and to the Institute of Medicine Roundtable on Literacy. So let's give Dr. Fernandez a warm welcome.

Keynote Speaker: Overview of Hispanic Health Research and PCORI
Alicia Fernandez, MD
Professor of Clinical Medicine, UCSF School of Medicine

It is such a pleasure to be here. I did the NHMA Leadership Fellowship and I loved it, and it was very instrumental for me in having me seek out and take advantage of opportunities that came my way. I recognize the training program, and think that NHMA has done a tremendous job in helping so many of us move forward. So I'm really glad to be here. This was a hard talk to put together because I wanted to say enough about PCORI that people who are not that familiar would know, but not be so boring that it would just be like reading the website, where you could get a lot of the information. So I sort of--so let me tell you what I did. I have no disclosures.

What I thought I would do is talk a little--give a little bit of broad context, all stuff you already know but that shapes my thinking; talk a little bit about my own research and then use that as an example of how that can be questions that are embedded in that research can be transformed into something that PCORI is interested in; talk a little bit about PCORI and PCORI's Latino portfolio and just maybe give you a few pointers on getting a PCORI grant. But we can--how many of you in the room are active researchers?

Okay, a lot of you look like very senior active researchers who really don't need
pointers from me on getting grants. And I see there are some junior researchers.

All right, so let me show some slides that you've probably all seen. This is the percent of the population that is Latino in 1980. It's about 6%. The deep purple are the counties that are over 25% Latino—so you can see obviously are in Texas and California. So here we are in 1980. Keep your eyes on what happens with the purple as I move forward in time, 1980; 1990, a lot more purple coming into different areas, 9% Latino; 2000, 12.5% Latino. We're really starting to see movement. 2006, 14% Latino, and now the CDC changes the coloring because the deep purple is now over 50% Latinos, which are over 50% counties. And 2010, this is now 17% Latino. As you probably know, we're about 18% Latino now. And can you see that there's purple all over the map? So there are a lot of us. If U.S. Latinos were a country, it would be the second most populous Hispanic country in the world after Mexico—so more U.S. Latinos than in my own native Argentina, for example. If we look only at U.S. Latinos who speak Spanish, there are 35 million. So that is more than Guatemala, Honduras, Nicaragua, and Costa Rica all put together. So Univision is the largest provider of Spanish-speaking content in the world. If we look at U.S. Latinos who speak only Spanish, no English at all, we're looking at 11 million people, and that would slot in as a separate country, right after Guatemala. Obviously, as you know well—we would be a separate country. We're much younger—median age of 28—and much, much poorer, with about 25% of Latinos living below the poverty line, as opposed to under 12%—12, 13% of the general population. We would be much less educated, much less legally protected, and a very heterogeneous country, with people who come from all over the world and with—though as a shout-out to my Mexican-origin colleagues, 64% are still the predominant Latino group—and also very heterogeneous in terms of levels of assimilation, acculturation, and status. About 35% are foreign-born, and about half are very recent arrivals, in the last decade.

We would also potentially be considered a separate country in health care, both for reasons of access, which has been improving dramatically, but a lot for reasons of quality of care. And as you know, the interactions between social determinants of health and our health care lead to both worse and better outcomes. So what does this mean? So I'm interested in diabetes. So let me just give you a few examples of how this plays out. As you may know, since 2000, one of out every two Latino girls and one out of every two Latino boys is, we believe, slated to develop diabetes. So we are at the early stages still of the tsunami. The worst is much yet to come.

Currently, over 40% of all people with diabetes in the United States are Latinos. To see how this compares, the diabetes in Mexico has been growing tremendously, so you can see Mexico in the blue bars, middle-aged men and in middle-aged women, and then in the green bars, Mexican-Americans—all significantly higher than the U.S. general population. So one of my areas of interest has been on the role of language barriers and what that means in terms of quality of care and outcomes of care. And I want to give you an example of questions that I've been asking and then work through that example to see how those can be adapted to a PCORI framework. I'm very interested with language barriers between clinicians and patients, and how do those impact our patients. Or is it that LEP status, having limited English proficiency, is simply a marker for all sorts of issues that could impact clinical outcomes?

And I use data from Kaiser, data from the DISTANCE study, which is a study of 20,000 patients from Kaiser Northern California, to look at that question. And here, you can see among 3,000 Latino patients with diabetes, you can see the English-speaking Latinos and non-English-speaking Latinos, huge difference in education, where about a third of the English-speaking Latinos compared to 70% of the Spanish-only-speaking Latinos had less than high school education attainment. And a significant difference as well in income.
Other than that, these populations were pretty similar with regards to some clinical characteristics, particularly how long they had had their diabetes, comorbidity scores, etcetera.

When we took these LEP patients, and we divided them by whether or not their doctor spoke Spanish—LEP patients with what we called language-concordant doctors and LEP patients with language-discordant doctors, we saw that they looked pretty similar. It looked as if the patients had almost distributed themselves randomly between doctors who spoke Spanish and doctors who did not.

But when we looked at what proportion had poor glycemic control, we found: among white English speakers at this time, 10% of the Kaiser patients had poor glycemic control in their last hemoglobin A1C, meaning a hemoglobin A1C over 9. Of the Latino English speakers, it was about 18%, and among the LEP Latinos, it was about 21%, which was a difference with the English speakers.

But when we disaggregated the LEP, looking at whether or not they had a Spanish-speaking doctor or an English-speaking doctor, we found that only 16% of the LEP with a Spanish-speaking doctor, a language-concordant doctor, had poor control, as opposed to one in three of those who saw an English-speaking doctor. This just shows that yes, that was, in fact, just as I’m saying, that there was an odds ratio of almost 2 between—if you looked at—1.98—between the odds of having poor glycemic control if you were LEP and had an English-speaking-only doctor versus an English- and Spanish-speaking doctor. So something about having a Spanish-speaking doctor was associated with much better glycemic control. So again, LEP, slightly more likely to have poor glycemic control, but differed greatly by the Spanish skills of their PCP.

When we looked, however, in the same cohort at lipid and blood pressure control, we actually found no difference, with about a third of whites, Latinos—and this looks different, but it isn’t—having poor lipid control and no difference by the language ability of the doctor, and likewise, for blood pressure, no difference—something that may make sense to those of you who, like me, are internists who work—it’s a lot easier to get people to take a statin once a day than it is to get people to do the very complex self-management and changes involved in ensuring good glycemic control.

And it is particularly difficult to do that across another language and across another culture. I see patients at San Francisco General. It is one of the most diverse hospitals—it is, in fact, the second most diverse hospital in the United States. The first is Elmhurst in Queens. We have 140 languages spoken per month at our hospital. I see lots of patients with whom I share no cultural reference, like many Cantonese-speaking patients. I assure you, it is very difficult to achieve good glycemic control across a language and cultural barrier, much easier for me to achieve good lipid and even blood pressure control.

So we start to disentangle these issues that seem to promote really different understandings of really different outcomes. And I don’t need to tell any of the internists or ophthalmologists or anyone else in the room what a continuous blood sugar hemoglobin A1C of 9 does to our patients. So you can see this.

In a follow-up study that is under review now, we looked at adherence among our Kaiser patients with diabetes to oral hypoglycemic: whites had inadequate adherence about 33% of the time, English-speaking Latinos, 46% of the time; LEP Latinos, 53% of the time. And there was no difference, surprisingly, by the primary language of their providers. This is at Kaiser, arguably one of the best places to support medication adherence, inasmuch as it’s an integrated system with lots of support for patients. Yet there’s something here that is going very wrong for our patients and for our communities.

Let’s switch now to talking about PCORI, and then I can work through how this could be applied. So you know that PCORI comes about through the ACA, and it’s authorized in Congress in 2010. And it’s governed by a 21-member board of governors.
I'm the only Latina on the board, and we can talk a little bit about that whole backstory, if you're interested. I've only been on the board for two years now.

PCORI funds comparative clinical effectiveness research. What we would say is that we seek answers to real-world questions about what works best for patients and their clinicians in real circumstances. The Congressional mandate for PCORI is it has to assist patients, clinicians, purchasers, and policymaking in making informed health decisions through research and evidence synthesis and disseminate research findings.

So why is our work needed? Because traditional health care research has not answered many of the questions that patients face. People want to know what option is best for them. And both patients and clinicians need information they can understand and use at the point of care.

PCORI believes that our work is unique because we focus on answering questions that are truly important to patients and those who care for them and that mainly because it's research done differently. We engage patients, caregivers, clinicians, and insurers throughout this research process. The hope here is that this means we're more likely to get the research questions right and study results to be more useful.

Who are our stakeholders? You can see lots of stakeholders. One of the things that is a challenge continuously at PCORI is balancing the different perspective of stakeholders because the perspective of purchasers and payers may be very different from industry and patients. Stakeholders are engaged in multiple ways, and I know that at least one of you here is on our advisory board for the Addressing Disparities portfolios. We have advisory boards, and other ways for people to be engaged who are clinicians, who are patients, who represent community groups, so this is something I really want to urge you to consider.

In terms of our research focus--PCORI funds comparative clinical effectiveness research. So what is that? It is clinical effectiveness research that compares A versus B. And that is great on many levels, but it can also be a barrier. And the trick is to tell people why your research question or why the things that interest us can work within a comparative research framework. So I cannot say I am interested in studying barriers and facilitators to adherence among Latinos. They will say, what a very good idea, but go to NIH with that. But I can say I am interested in studying whether this intervention or that intervention is better for promoting adherence to diabetes medication among Latinos. And as part of that research, obviously, I may need to figure out barriers and facilitators. But they will be interested in funding that part, inasmuch as at the end of the day, I'm doing a trial that compares A versus B. Does that make sense?

PCORI is also particularly interested in real-world populations, as opposed to more laboratory populations, wants to know more about how things work in some groups of people, and we already talked about the whole point of it being to make decisions.

We have five areas of research: clinical, comparing the effectiveness and safety of different treatment options, prevention options, diagnosis options, and comparative questions in healthcare. For example, in the PCORnet network, we have a large study looking at for patients who need to take aspirin for heart attack prevention should--what is the right dose of aspirin. We don't know. Should we give them 81 milligrams? Should we give them 325? Improving health care systems--there has been a lot here of interest to people who do Latino disparities research. This supports patient self-care, innovative use of health information technology, care coordination. We have a lot of studies going on on promotoras, patient navigators, et cetera.

Communication Dissemination Research supporting shared decision-making and figuring out how to disseminate research to people who need it, both patients, families, and physicians. And then our Addressing Disparities portfolio, which I'll talk a little bit more about. Finally, we have a whole portfolio on Methods, how to improve methods related to outcomes research.
So the research criteria has to be to fill a critical gap, generate actionable evidence, potential for the study to be adopted into clinical practice, scientific merit. We look at patient-centeredness and patient and stakeholder engagement. And I'm going to say a little bit more about the last two because those are different from what NIH or AHRQ looks at.

What do we mean by patient-centered? The project aims to answer questions that matter to patients. So someone was giving me an example about bronchiolitis research just now. And one area that may come up in discussions with patients is that the appropriate outcome might be does the kid sleep through the night? So that is an area where patients could influence the outcome, as well as influencing the research protocol. There are many other outcomes other than mortality that matter to patients and to their caretakers around quality of life and around treatment burden. And those are the types of things that PCORI is systematically trying to include in our studies.

The other sort of criterion is patient and stakeholder engagement, where patients have to be engaged from the beginning, with the scientists who are carrying this out. There's a priority given to high-priority conditions. So the Addressing Disparities portfolio has funded to date 61 projects. Of the 61 projects, 31 are focused primarily or substantially on Latinos. There's a very broad range of topics--health services, use of technology, navigators, language barriers and clinical areas--serious mental illness, studies on depression, stress, alcohol and opiate use, cancer screening and a large portfolio, a cluster of studies around asthma.

Let me just talk about that. The asthma goals are to reduce poorly controlled asthma in both the African-American and Latino populations, and doing that in a variety of ways. And this just gives you a little bit of a sense of what we're doing--what studies have been funded--so using IT to improve access, a study out of Pennsylvania. You'll see that these were all Randomized Clinical Trials using a family community intervention versus a clinic community intervention out of Imperial County: studies looking at asthma care coaches; a study looking at the use of more of a clinical study; the middle one there, out of the Brigham, looking at use of a daily inhaler versus the addition of a symptom-based asthma medication; another study looking at what to do after people leave the ED. And then here's another one looking at health plan guidelines seeing whether or not there's some way in which the guidelines can have additive interventions to see what do we actually need to do to help providers, quote/unquote, "get with the guidelines." So that gives you, I think, little bit of a sense of a cluster area that PCORI is working in.

The things that may mean the most for the junior or even senior researchers here are broad funding announcements. These are similar to an NIH R01-type announcement. Unfortunately, they have about the same amount of success rates as the NIH, which is about 13 to 14% success rate. Unfortunately, it's quite hard to get a PCORI grant. That said, PCORI has a lot of money and needs to spend it. And so there are many opportunities here.

What is nice is that it's a two-stage application process with a letter of intent. And if the staff doesn't think that the idea fits in within the PCORI framework or that the patient engagement or plans for patient engagement is not robust enough, they'll turn it away right there so that it makes it easier. And that's included within the 13 to 14% figure at the bottom. So it makes it a little bit easier that you get early feedback.

And just to make sure people know, the merit review process has not only scientists reviewing the five criteria, but patients and other stakeholders who score the potential for the clinical findings to be adopted into clinical practice. They score the patient-centeredness. And they score patient and stakeholder engagement. All of those scores come together into the final score. This obviously is very different from NIH and AHRQ.

So we think that engagement needs to be in every path, from the review to dissemination to topic selection, and that people need to look at the engagement rubric.
Have patients been involved in planning the study? Have patients involved—you may go from talking about compliance to adherence. And we may not even need to talk about adherence but rather barriers to medication use, instead of putting it on the patient—how the study will be conducted, disseminated in the results, et cetera.

There is another type of award, which I mention just for the junior researchers. PCORI Engagement Award, Pipeline to Proposal—we've given out—there's been $12 million already awarded in that category. It's a great category for very junior people who want to work in this area.

So if you're someone like me, just to give the example, and you want to think about how PCORI can help with my research question. Well, first thing I need to do is think about it as framing it as a comparison of interventions. And I can say—I can have usual care be one of the comparators. But suppose I want to study, I don't know, the use of peers to enhance diabetes, peer educators to enhance diabetes adherence to medication. The usual care can be a comparator as long as I'm very clear in saying what that usual care consists of. I need to seek out patient input from the start. Am I working with a patient advisory group, am I working with a community group, or both? I need to think about how to frame the questions in a way that's most appealing to patients and consider that recruitment. And finally, I need to set guidelines and milestones for how patients, other stakeholders, and myself and my team are going to interact—how often we're going to see each other, what are going to be our milestones for achieving success. And I need to say what's going to happen the day after the results are in. How will I use these results—how not will I—how will we--patients, researchers, the team--use these results differently once we get them. How will it make an actual difference?

You can see that's hard, and it's taken the research community a number of years to start learning how to successfully write these grants. But it obviously can be done. And I do actually think it makes for much, much better research, particularly for those of us who are interested in disparities issues or issue that are more common in the Latino community.

So I do think there's an urgent need for patient-centered outcomes research among Latino patients. And I think we have a huge need for more innovative questions and research partnerships. I want to urge you to apply for PCORI funding, for those of you who are researchers. The board is firewalled from the merit review. Obviously, besides the fact that we can't apply for funding, I can't help you get your grant in—help the grant go through. But I can give all the advice you want on how to write it. I'm happy to look at it. Many of us—there are many people who would be happy to help you. And anyway, this is a great area for research and an area which I think could really use a lot more Latino input.

**Discussion on Priorities from the Group:**

1. Care Coordination research needs to be disseminated to health systems – how does PCORI help? For Latinos, this is especially important with community health workers who can be key players in coordinated care models which research can be supported by PCORI.
2. There is a need for partnerships with Hispanic clinicians with academic researchers, both PhDs, researchers and NHMA Conference could be a venue to bring them together to discuss new research models.
3. After the study is done, PCORI has dissemination grants that are given to projects to really help people disseminate. So it's not only funding the research—which NIH or AHRQ does—it's also funding dissemination that is important to building research knowledge in our community.
4. There is a need for more Latinos to work at PCORI or to be on review committees to advocate for Spanish materials for LEP potential patients. For example, most PCORI studies are funded with only English materials, as is a new LGBT definitive study. This
group together with NHHF needs to recommend efforts to develop researcher database for nomination to PCORI and other efforts.

5. In terms of complex care cases and care coordination, we're starting to see that it is a big challenge, that you have comorbidities that are occurring and how receptive would PCORI be in terms of some of those studies, as well as looking at multidimensional views of diversity. So, for example, Latinos who also are disabled or might be veterans, socioeconomic levels is important to future research.

PCORI's doing a ton in complex care management and I think would be very open to a more nuanced view of diversity. Like a lot of majority organizations, it still has a ways to go. But we should be pushing that. We should be up front about that. And what our colleague said, cheerful persistence. The social determinants of health need to be included in PCORI research and recognize that there are so many other aspects that affect our health--housing, education, you name it. And I wonder if PCORI is starting to examine those potential areas and integrating them into examining to what degree we make an impact in the outcomes.

Hector Balcazar, PhD, M.S.
Dean, College of Science and Health
Charles Drew University of Medicine and Science

Hispanics and Latinos are tremendously suffering from diabetes and chronic diseases. And there's a tremendous amount of problems associated with some of those chronic diseases, even though paradoxically, we have good outcomes. So there's a lot about risk and Hispanics that we have to really think about. And so when we begin to dwell upon diabetes and hypertension, we are beginning to see another story about lack of control.

So what are some of these challenges and opportunities and how should we really conduct research in Hispanics? Choose your passion. Choose the things that you like. And then once you do that, then you begin to start thinking about establishing collaborations and looking at data. I remember when I first started my career in prenatal health, actually I used data from when I was in Phoenix to look at low birth weight in prenatal care and issues of breastfeeding. And I found out that low birth weight rate was really similar to whites and very different from African Americans - the Hispanic paradox. And so that was interesting because of the data they were showing.

Working with communities is an art and that to be an artist, you can be a scientist, but with the idea of promoting a lot of community-based participatory research and engagement and that there are concrete steps that one can do to really get what you want to get.

So my story is that we have seen so many times health care is too expensive. We need to do something about it. We need to really align efforts to move from disease conditions to prevention. PCORI was actually centered into that idea of looking at patients and begin to start transforming that.

So we know that the empowerment model of public health is really important because, as we know, prevention accounts for 25 years or 30 years of life gained in the past century. So public health has been incredibly important. So with public health, we can address how we begin to start connecting public health with the idea of patient-centered, and how we can move the idea of collaboration within the context of care.

So this is from Dr. Nancy Dickey in Texas, who talks about where should we move. We should begin to move outwards. Physicians, many of you, are working hard to move it outward, to move it to handshakes, to try to get incentives to collaborate, to partner, to do
interdisciplinary training, to build better teams. So that’s where I come in. So come in to start thinking that, in many ways, we believe that this is a possibility. Where can we inject other models?

And Dr. Fernandez was mentioning the promotora model. We’ve been working for many years with this model to try to see whether we can begin to start nesting it in clinics and community hospitals and then start integrating the prevention protocols in a more ecological way. We have a tremendous model in the community. And there is now scientific, clinical, and comparative effectiveness evidence that indeed this model works. And I’m going to present just two examples of that. Because it is a very effective model—once you start moving along with people, promotoras train family members. Family members train other family members. You can imagine the democracy of health that can exist.

So the idea is to begin to work on this model.

So we worked on for many, many years the idea that the physician comes in a standard way, the visit, the assessment takes place, the education can be verbal or on printed handouts, a treatment plan. And now, all of a sudden, we begin to start partnering with the clinics and the communities and say hey, physicians, could we just get you to work with promotoras or community health workers. So you give us all your diabetics and your hypertensives and some of your obese individuals and some people that really would like to do more prevention. We put them into promotora models. We train them well. We get them specific programs. We standardize the education. And then we test it in efficacy or randomize or pre/post designs or all the kinds of designs and see if it works.

What happens when it works? Then the physician sees that one month or six months later, their hemoglobin is changed. This is just one example of things that have been—if you look at the literature right now on diabetes and community health workers on hypertension for African Americans, for Latinos, Asian-Pacific Islanders, you will see that using randomized trials, pre/post designs, other kinds of methods, there has been some efficacy. And we need to then move to effectiveness working in communities. So this is something that can occur.

So the idea is there would be tremendous opportunities for integration. So this is very exciting, and I invite all of you clinicians and physicians who are working really hard in your communities to begin to partner with researchers and community practitioners that believe in some of these models of care so that there will be frequent communications. There will be a tremendous organization of opportunities for the community to get engaged. And there will be opportunities to begin to change those outcomes.

We have actually done some randomized trials at clinics. And we found that sometimes, it’s expensive to go to communities and try to get 5,000 people or to get 300 people and divide them into controlled and randomized designs, although it is important to do. We can begin to start working in the clinics and working with communities to begin to see changes. This was a reflection of this intervention that shows improvements in some of the parameters that are associated with weight and cholesterol and so forth.

But then, if we think about it, we can expand even further. We can say, not only can we do things in clinics and communities, but the doctors today say we can partner with the YMCA. We can partner with the Parks and Recreation, and we can do an environmental life programming that relates to lifestyle and nutrition. For example, with programs like Salud Para Su Corazón, Health for Your Heart, that has been tested many, many, many years. And you can see the literature on that. That was related and created by Latinos for Latinos. And we have made sure that that model has been tested many, many times with many, many researchers. But we can begin to look at charlas and beginning to use some of the fotonovelas that I gave you that are the CDC so that we can begin to engage the community. And then we can not only do that, we can do grocery tours with the promotoras to use some of this information. And then we can do charlas and also work
with the Parks and Recreation to do dances, to do grocery tours. We can do a variety of things. And it works. We have just published this in *Health Promotion Practice*. This is very powerful. There are not that many studies that show that community resources with promotoras can begin to change behaviors like eating fruits and vegetables and decreasing weight.

But always, we have to believe in the family, in the culture. We can always believe in the idea that brings specific messages, integrating programs that work so that we can begin to start really making some of the solutions because people are very confused about it. And so sometimes just going then to the dietitian is not enough. It's just hard for the person to understand what 24-hour recall and calories and 2,000. The people need to be in a very different engagement. They're not to be trained and tell them what to do. They need to engage them. We need to be less paternalistic and more democratic in our thoughts.

We need to move from traditional models to new models of care. We need clinical community interfaces to improve, but we need to do CBPR, Community-Based Participatory Research, so that we don't think that we know it all. We need to go to communities and tell them, you are the ones that are going to solve our problems.

And we need to change infrastructures. We need to change models. We need change the CMS. But we need to give them the idea that this can be reimbursed, the physicians can work with clinicians and educators and community health workers to start reimbursement. And we're working really, really, really hard, community health worker advocates, to do that. And we need to integrate models so that we can look at prevention.

**Greg Talavera, MD.**  
**Professor, Public health,**  
**San Diego State University Graduate School of Public Health**

I'm going to present a model of care that I started with NIH support ten years ago that is embedded in a community health center between major players in the Latino community. San Ysidro Health Center in the middle is the largest provider of indigent care in the south region of San Diego, with 90,000 registered patients and 15 clinics and 60 primary care doctors. San Diego State University is home to a school of Public health. And UCSD is a major player in cardiovascular disease risk profiles.

Key to this is what I call is a partnership clinic. It's a true CBPR collaborative clinical facility. We do cultural competency, and we include physicians and patients in our work, and administration because we have to have a model that's economically viable for the environment that the community health centers work in, which is prospective payment.

So because of my understanding of that, I'm able to design something and work to meet their needs and is in the direction they want to go. I use the research money to help them get to where they want to go with a little bit more resources and to test the efficacy and show to them that it works, hopefully. So the work that I do is definitely a base of the community. We are developing infrastructure around the research that we do including a center that has a large database and a data analyst. We bring folks in that want to do their work.

Since I wear two hats, and I'm also the director of research for San Ysidro, I broker relationships with all the researchers in the community that want to access the patients.

The other part of this is that in my time working with this organization, I have helped them realize the importance and benefits of the center and this kind of work in their mission, which is to deliver good, high-quality care. And I think--I started about ten years ago with this model and this kind of work, but it's timely because we know that payment reform is on its way, and I think this model will fit right into what they need to do.

The mantra for the work that I do with them, and whenever somebody comes to the
community and wants to access their patients, it's got to be mutually beneficial. So for example, most recently I had a researcher that wanted to study Kawasaki's disease. And she wanted to come and, I don't know, mine our database and everything. And I said well, what's in it for the clinic. So as broker, as their director of research, I always say it's got to be a benefit to the patient, the organization, or the community. If there's not that mutual benefit, I don't think they're going to go for it, which means I'll sabotage you. So this is what each of the three entities contributes right now. We have a major medical academic center at UCSD with people that know how to do carotid studies and echocardiography and things like that, and they work with me. San Diego State, which is largely a teaching university by charter, does a lot of research, and that's where I'm based. And I help a lot of my colleagues there.

San Ysidro is a large, federally qualified community health center. So working with them and the fact that they are serving indigent and underinsured patients and uninsured patients makes our model very replicable. If I can do it in this health center, I think I can sell it to others. And I've just done that with another sister clinic up in the north county. But they're well-run, and they recognize the benefit of having research in their center.

I have also developed what I call the South Bay Latino Research Center. It was originally funded by the National Institute for Minority Health and Health Disparities Center of Excellence. The predominance of the Latino community lives there. So this is the facility where we house what I call the partnership clinic. It's a medical facility right next to the major indigent hospital, Scripps Hospital in the heart of Chula Vista, which is about six miles from the border and six miles from downtown. We have about 18,000 square feet there. We house the landmark Hispanic community health study there. But the rest of the space is what I love to do, which is intervention research. We have two major clinical trials, one for diabetes, one for childhood obesity. And as I mentioned, they now represent 90,000 registered patients. Out of that, we have 5,000 diabetics that need help. And we're trying to work with them. So it allows for a good population-based sampling.

So what are the resources in the partnership clinic? SDSU provides the clinical and classroom space and the infrastructure, telecommunications, data warehouses, and so forth. San Ysidro for our studies, for our randomized clinical trials that provide their actual physicians and behavioral health clinicians to come into the partnership clinic and actually see patients in a randomized fashion--well, they're the intervention phase. But it's nice because it's a controlled environment. And the way we accomplish this was that San Ysidro, after a few years, decided, well, why don't you become a satellite clinic for us? So we became authorized under the FQHC guidelines. We staffed it with all the equipment that it needs. We got it licensed. And two years ago, they put in their EHR system.

So when we see our intervention patients at the partnership clinic, they're actually billable visits. They're logging into the EHR. We do our care coordination through the EHR, and we set the appointments through the EHR. So it's become a really nice laboratory, so to speak, that's real life, using real-life clinicians and so forth, and again, bringing in the expertise from UCSD as needed.

So I don't need to go into the patient centered medical home, but we're largely focused on chronic diseases. We have as elements of our model a specially focused clinical team. We have a behavioral medicine specialist, which is me sometimes. And I train the people that come in from the health center. We also get clinicians from the behavioral health Department of San Ysidro. And we use peer-led health promotion and trained care coordinators.

So what are the key features of the intervention model that we use right now? Well, colocation of the service--we followed the AHRQ integrated model of care, and we took it to the highest level. We do the highly integrated model, where the physician, the behavioral health consultant, and the promotoras are all in one clinic. And they're all
focused around the patient. We do the warm handoffs because there's a lot of stigma about going to mental health or behavioral health. So when I walk my patient next door to the behavioral health consultant, I introduce her as my colleague and a team member. And there's no sign out in front that says mental health or behavioral health. It's just the clinic.

And we use shared decision-making in our approach to the patients: what do you want to do? You've got all these behaviors you've got to change. We do a lot of integrative and reinforcing messaging because the promotoras, the doctor, and the behavioral health people are all talking together as a team about the condition that we're targeting. We're allowed to use the EHR for recruitment. We sign HIPAA agreements and contracts so that research staff and employees of the San Ysidro can do the recruitment. And this is what the model kind of looks like in a graphic version. We have the patient-centered self-management goals here. But as I mentioned, they usually see the doctor first up here, the trained physician specialist who does the clinical assessments and the risk factor assessments. The behavioral health consultant will screen for depression and anxiety and relationship problems and things like that. This exchange takes place the same day, so it's an ideal world.

And then they attend six courses led by a promotor, but all focus on the same thing. And then, of course, we have care coordination, and as Hector was talking about, linkages to the community.

So that's what the clinic facility looks like. It's very modern. Patients like it because it's not crowded, and they're the only ones in there. San Ysidro itself is actually moving way beyond what we're doing right now. All their new buildings that they either buy or construct are now going to what's called the bullpen model. So what we have established in the luna model, they've already, in their most recent building, have designed their clinical facilities where all the doctors and behavioral health consultants and care coordinators are in one facility.

This is not new, but it's pretty new for a community health center to design that way. So that way, there can be warm handoffs. There can be exchange of information. There can be co-management and all those good things. So just very quickly, I've been working with this organization for 30 years, my first 10 years as a physician doing a little bit of research, and then the last 20 years, a researcher trying to do a little bit of clinical. But it is very place-based. And again, that concept of mutually beneficial partnerships. The other key thing that's helped this move along and expand to the level that we're at is within the community health center, we've developed their own research and health promotion department. So whenever we get the randomized trial grants, the intervention portion of the grant is subcontracted to San Ysidro. So their promotoras get the expertise. Their program managers learn how to do randomized trials.

They're very sophisticated now. They understand the importance of randomization, and they understand the importance of measurement versus intervention. Randomization doesn't blow the administration out of the water, so they get it. We report back to their Board of Directors. We share our results with their clinicians. We're often part of the adult medicine team, and so forth. And that was started in 2003 by myself.

But it's more than a research center. It's really a health promotion center, too. And all the projects, they do about 1.2 million a year in grants, some from the university, some of their own. And they fall on the spectrum of randomized trials to service-oriented. So we do serious planning with the physicians and the staff of the health center. We explain our models to them. We have a routing form to get the research through administration, so the CFO, the CMO, the nursing department all understand what we're doing, and so it's signed off on. And we also do a lot of mentoring. So our center is also a big place, an attraction for students from MPH to post-docs.
Hispanic Health Research Training: Lessons Learned in Patient-Centered Research Training for Hispanic Stakeholders Including Patients

Aida Luz Giachello, PhD
Professor, Department of Preventive Medicine
Feinberg School of Medicine, Northwestern University

My objective is to talk about some of the challenges involving the inclusion of Hispanics and Latinos in clinical research and some strategies to be able to address that. I know that Dr. Fernandez already talked about some key facts, but I always wanted to remind the audience that in 2013, we already had 54 million Latinos representing 17% of the U.S. population, and 1.1 million Latinos being added every year to the United States. And by the year 2060, 31% of the total population, 128 million, will be Latino. And in 2060, one out of three will be Hispanic origin or background. And we are expected to be, by 2060, the second largest Spanish-speaking country in the world, Mexico being number one.

Dr. Fernandez already did a wonderful job describing research in patient centers, so I'm not going to be talking about that. I just want to say that as we talk about the Latino population, we need to take into consideration the economic impact. The Latino purchasing power increased to 1.5 trillion in 2010. And this is critical, because now corporate America, everybody's looking at the Latino because we are really moving the economy here, and our pattern of product consumption is different due to our age and diversity. So keep that in mind. The purchasing power is really making an impact.

Now, let me begin by saying that, in 1991, the Agency for Healthcare Policy and Research, in response to congressional mandates, launched the medical treatment effectiveness program. So I've been doing outcomes research, because as a result of this mandate, the Agency for Healthcare Policy provided funding to establish 11 med-test centers, as it was called at that time, in addressing minority populations. So I was able to submit a grant to compete for that center grant, which called for patient outcome research, for comparison research. Most of the studies that I've been doing since 1991-93 are outcome-related. I've been doing community-based participatory research before the term existed because of my unique academic background in medical sociology and social work. For example, in my research I was able to use community strategies of mobilization to engage community partners and stakeholders and add more stakeholders.

And obviously, we all know that the importance of research is critical because it has tremendous opportunity for policy development. We learn through comparison research Hispanic versus minority, Hispanic versus other minority, Puerto Rican versus Mexican American so all of that really is critical in terms of legitimizing the research on Latinos. The problem has either been not sufficiently studying any population or not sufficiently studying the Latino population or the nature of the problem appears to be different in the Latino population.

Through my experience in clinical research and other types of social science research, the greatest challenge I have recognized is the limitation of data available for planning and conducting research. Dr. Talavera didn't say anything about the fact that he's the PI of the San Diego Field Center for the NIH longitudinal study that we call Community Health Study, Study of Latinos and I am the Co-PI for the Chicago Field Center, this is the one of the critical challenges that we experience. This is a national multi-site epidemiological study on cardiovascular-related conditions. For example, a data-related issue came about in our recruitment for the study from the gentrification in Latino neighborhoods in San Diego and Chicago that forced us to reconfigure the sample in other localities than the originally planned neighborhoods based on the last Census.
Similarly, Miami which drew their sample thinking that the Cuban and Cuban American was going to be in a certain locality, they have had problems in recruiting the Cubans due to death or moving their residences. So this is a reality of doing research on Latino. The data sometimes is not useful enough particularly at the local level to be able to draw new sampling and to be able to come up with a good research design.

We also found collectively that another issue was instruments and measures not being adequate and not validated for Latinos and were based on middle class ideology. They really had a number of problems and we had to come up with our own instrumentation and later began testing for cultural appropriateness and related matters. Instruments are not developed in Spanish or are literally translated. It does not include an acculturation measure and are not fully tested for validity or for sufficient pretesting for cognitive validity so there's also a number of biases around racial and ethnic lines, socioeconomic lines, citizenship status, gender lines, and it's difficult to adapt to populations with low levels of health education and low levels of literacy.

The patient, family, and community engagement in patient-centered research is important, and everybody wants to go after this type of grant but what we are finding is that researchers, particularly in the medical field, don't have the skills, the understanding, the knowledge to be able to reach out to the community to work with the gatekeepers, to be able to participate in research activities. So I always get bombarded about ideas on how to go about getting the patient perspective and how to design a program that is patient-centered. So those are still very serious problems as we try to move into this field of patient-outcomes research. Obviously there's limited funding to conduct research on Latinos, but we find it's very difficult to do a study without sufficient funding to recruit, enroll, and follow up on Latinos who are highly mobile. In addition, we need to develop, translate, and test culturally appropriate instruments. We need to develop appropriate sampling frame including over sampling and all that is very costly. There's also limited funding to conduct Latino research, particularly patient outcomes research, in terms of establishing procedures and training research staff to assure high quality of data collection in field work, to engage in meaningful intervention in follow-up activity, and to recruit and train minority investigators and to even achieve high response rates.

We have been successful with the Hispanic Community Health Study, Study of Latino, because we really involve individuals from the community (community health workers) who know the language and culture, who live in the community and facilitated the outreach to patients and the recruitment process. We were able to recruit 16,000 Latino of diverse nationalities, the first study to have a very health sample size of Mexican, Mexican-American, Puerto Rican, Cuban, Dominican, Central and South America and for the first time we're going to validate many of the other studies that have been done and pilot efforts to see the differences between the different Latino groups.

Another challenge that we had in trying to get Latinos in our sample was the distrust of the federal government. On the one hand we were in a certain community recruiting, and on the other hand, you have immigration officers taking people away so it was very difficult for people to open the doors to engage in our efforts. So we had to come up with a serious strategy, developing DVD, about the study, DVD and the consent form, DVD and genetic testing because that was part of the many procedures to be done and it was really a challenge but we were able to go through them. People, you knock on the door. First of all, when you send them a letter inviting them to be part of the study, you find when you visit two weeks later that the letters fell on the floor because they didn't have a mailbox. You try to ring the bell, there's no bell connected to the apartment. I mean, we have to really talk to the - - and other elected official to help us and even to the tenants organization, owners of those buildings to be able to have access to those facility and be the recruitment.

From an early study that we did, we found that 88% of clinical research is from
academic cancer centers. The study we did was on reported cancer recruitment and retention. With the exception of the media, they have no knowledge and skill on how to reach out to minority and women inside or outside their institution. Some of them say that they can't even recruit in their own hospital because of competition for patients between departments and units, lack of internal referral system, because of low institutional commitment to serving minority and women and then already have been alluded the whole issue of lack of medical care. Most of the patient outcome research requires connection with clinician and with healthcare facility and we know that until recently, Latino was least likely to have a medical home and least likely to have health insurance. From the patient perspective, one of the problems that we confronted with the project was the limited knowledge and understanding about what is research. People just don't have a clear understanding of the importance and benefit of research, so we had to develop effective promotional material. Other barriers besides linguistic and cultural barriers include work schedules, transportation, babysitting arrangements. Thus, for our study we had to either, in the case of New York, with the center there, Dr. Kaplan is the PI, he had to give vouchers for taxis, in Chicago, we came up with vans that were able to pick them up so they could be able to come to the clinic because it was eight hours of physical exams that they had to take. So a number of concerns related to the patient and how to engage them meaningfully in the activity and the lack of trust in research is due to history of oppression, abuses, and violation of individual rights that have occurred among Latinos and African American and many other.

So strategy number one is gaining familiarity with the Latino community and with the specific Latinos being studied. Part of that effort is to do qualitative research and the graphic study, focus group. In that interview they could help you understand the community in question. Then other strategies to establish research partnership consortium, which the - - really calls for, with multiple community-based organization like I was saying before also would help human services organization and part of that partnership has to be based on equal basis, you have to share the percentage of indirect costs.

When I started partnering with the community in the 1990s, my dean was the first one who was very upset because that meant that the research grant from the federal government had to be shared with the community and he wanted to keep all the indirect costs in-house. There is a challenge like this depending on academic leadership. On the other hand, the community challenges include their desires for job opportunity like serving as the interviewer in studies. You could hire the community to do that or do focus group. You could hire community-based organizations. They want training opportunities, some of them particularly physicians want co-authorship in manuscript if they are actively involved.

As I mentioned before, we generated a series of other educational pamphlets and DVDs and we also needed strong and complex infrastructure. We had many committees to be able to address a diversity of issues in regard to this Latino study. We needed to establish a meaningful advisory committee that you have to work with and educate them up front that they cannot change certain agreed upon terms approved by an NIH-funded grant, and we had to tell them no, we want your meaningful participation but there are certain areas that we just cannot be able to negotiate with the community because they already have - - agreement with the federal government and so that involved really helping people understand some of those commitments and to what degree they could be instrumental in providing meaningful input in certain areas. As for strategy for dissemination, we worked with a CBO, National Hispanic Health Alliance and NIH and developed a pamphlet with information for the community about the results of the study and this produced discomfort for the investigators because they were concerned they would not be able to publish a
manuscript. At that time we didn’t have a manuscript ready but it was clearly decided that we would publish reports and place them on our website. They have very simple tables so community leaders can immediately use them for grant writing, for understanding what's going on because we are constantly giving report of the findings to the community through community town hall meetings and forum. This other pamphlet to the right is a booklet that was developed for the patient. The patient has the right to know the study results in a study that he/she has participated in. Here are examples of how we have been interacting with the media by having the PI discussing the study at a press conferences announcing the key findings. Another challenge is the lack of research about the second and third generation of Hispanics. When you look at the data, the data indicated that the second and third generation appear to have higher teen pregnancy, obesity and other chronic diseases earlier in their youth, mental illness including anxiety, panic attacks, alcohol and other addiction, tobacco use, different types of cancer and that someone we are being focusing on immigrants, which is wholly support and I think we should continue but we need to balance that with the second and third generation because the parents, they come here in their effort to improve their economic wellbeing. They work two or three jobs. They somehow are not as physically accessible to their children and as a result, their children tend to engage in gang activity. If you hear about what's happening in Chicago, you know, there's 75 deaths every weekend and those are violence in the Latino and African American community. We need to figure out a way to address those issues.

Another area that I’ve been working in more recently is tobacco. Currently, the use of hookah and electronic cigarette is emerging as a kind of epidemic. There's very little regulatory policy. There’s very little research that has been done. We did a couple studies in collaboration with Dr. Talavera in San Diego, in Miami, and in Chicago as well as studies with the gay and lesbian, bisexual community because the use of not only cigarettes but also hookah and e-cigarettes is very high among those population as well. One of the things that we have found from the Hispanic community health study is that Puerto Ricans have the worst health status in a number of indicators from obesity, sleeping apnea, asthma, to depression. For a sample of Central and South Americans, they are doing much better in these indicators and we need to figure out how can we begin to distinguish prevention and intervention in addressing those populations.

Puerto Rican have 36% asthma much higher compared to the Cuban, Dominican, Mexican, and Central and South Americans. When you look at percent of diabetes, you find that it is more common across most of the group in terms of this particular condition but still high at over 18, 19% for the Puerto Rican. When you look at the prevalence of cardiovascular risk factor by Hispanics, in this case men, you clearly find differences by Cuban, Dominican, Mexican, Puerto Rican, Central and South and American origin and a number of key indicators that have been associated with cardiovascular. So all this data emerging from the Hispanic community health study is indicating that we need to figure out how we can propose interventions that would target Latino subgroups because of the emergent differences that may exist in a number of health indicators. When you look at multiple cardiovascular risk factors by age, you find out that we have people over the age of 65 have three or more risk factors, either they have diabetes, high cholesterol, hypertension, et cetera, and you see the differences by age group. I was curious that 12% of those between 18 and 44 already have three or more cardiovascular risk factors and this is something that again we need to look at it very carefully in terms of the intervention needed. We need to reinforce the whole notion that their health status varies and then in ending, the long term benefit of the Hispanic community health study, we need to add knowledge of cardiovascular in current disease risk factors to effectively prevent such disease.

We need to identify health disparities in areas of greatest need, provide baseline
data for future Hispanic studies. We can be successful at recruiting people when we develop the kinds of strategies that are culturally and linguistically appropriate with appropriate resources. The Hispanic community health study started with $62 million and now it's at close to $100 million at the second stage of the project. It is going to help us eventually to understand the process of Hispanic health research with the instruments and procedures that we have been developed, it could be used by many other studies and it has served as a training ground of many new Latino investigators that are part of those efforts through the Hispanic community health study and the data we expect will lead to health policy that will benefit Latinos in the short and long term, as well as in the progress of research with cultural appropriateness in the study, promotion, recruitment, and retention.

David E. Hayes-Bautista, PhD.
Distinguished Professor of Medicine,
Director, Center for the Study of Latino Health & Culture
David Geffen School of Medicine, UCLA

Our Center started a course for our UCLA fellows and I've included other doctoral students on theory, method, and data in Latino health research. Most of the literature on Latino health research has been done by a faculty that know nothing about Latinos except basically what they see on the 11:00 news at night and as we look at theoretical models, primarily they're based on some variant of the traditional culture, the family, machismo or the urban underclass model or the culture of poverty model or the assimilating immigrant model. They'll be some variant of that, then they've been operationalized and boom, boom, boom, and then they can't explain stuff.

They look at census data and report: "Wow, more people and more Latinos are speaking English that means they're assimilating. Soon there won't be any more Spanish and they could be my Croatian or Yugoslavian forbears and they're going to assimilate away." Well, not quite. That's part of that assimilating immigrant model. If the assimilating immigrant model really held in California, the last time Spanish should have been spoken, should have been about 1880. By the way, the average Latino in California has been born in California ever since 1790. The immigrants have always been a small group of the Latinos in California. So you can somehow track this assimilation and - - that's going to tell you a lot, still doesn't work with Latinos but we still use the models and in terms of patient-centered research, we really need to think about what models are we going to use?

If we want to understand the context of patient experience and how we do patient engagement, we need to understand the theoretical models we have of Latinos and how Latinos put their world together. Patient activation, patient self-management or community and clinic interventions and as we move towards accountable care organizations and globalized payments, which is another way of saying prepaid capitation, we need to understand how do we do this with Latinos with the health profile that Latinos have.

For the past three years I've been on the governing board of White Memorial Medical Center and working with Dr. Hector Flores planning a Center for Hispanic Health that's going to look more pragmatically about these issues as they are applied at White Memorial Medical Center and I want to share with you some work we're doing creating metrics for wellness. We're going to be responsible for defined population, prepaid capitation. We know how to treat illness. Do we know how to manage wellness for Latinos? What is Latino wellness? Well, as it turns out as we look at the data, actually an ACO with a Latino population base has got a huge subsidy. But you wouldn't know it. As we look at most metrics, when people want to look at the wellness of a population or
defined area, they look at racial minority problem, lower income, problem, lower education, problem, less access to care, problem. Well, guess what? Latinos have all of that. And in fact I was just looking at the most recent Institute of Medicine report, and they're talking about metrics that matter for population health care. The primary drivers of poor health outcomes are race and poverty. Well, guess what Latinos have? We're race and minority and we're poor. Going a little bit further, health disparities across neighborhoods exist for a variety of reasons including education and income. Low education, low income, racial minority group. But what is the effect of all of that on the wellness. Well, let's just took a look at healthy people 2020.

As we look at their chronic disease goals, their first goal is to get the coronary heart disease rate death rate down to 103.4. Well, you notice non-Hispanic whites. Higher income, higher education, better access to care. Hey, they're white, they're not minorities, you're not them and have not yet met that goal. Latinos nationally have met and exceeded that goal tremendously.

Number two cause of death: Cancer, of the people 2020 is to have that down to 161. Non-Hispanic whites still haven't achieved that. Latinos have met and exceeded that significantly. Stop and think of services you're not going to need to have to supply. COPD. Healthy people goal's 102.6. Non-Hispanic whites way above that. Latinos have met and exceeded that substantially. Stroke deaths. White folks still haven't got the message. Latinos somehow have got the message. Infant mortality. Well, both groups actually are doing pretty well. Actually both have met and exceeded the goal. Cigarette smoking. Actually Latinos are just a tenth of a percent away from meeting that goal. Non-Hispanic whites are quite a ways away. But of course as we look outside of that, just all age-adjusted death rates. This is that crazy Latino epidemiological paradox only now there's going to be dollars tied to it under global payments.

If you're worried about providing care, heart, cancer, stroke, et cetera, and you have Latino enrollment base, you got a huge subsidy but how do you keep that from changing. How do you manage that wellness and at the same time treat some illness. And I've been arguing with IOM and Robert Wood Johnson don't apply those metrics to Latinos and in fact we're also starting to look at Asian populations and we're saying you know what? You need different metrics if you have a diverse population. Maybe those metrics work in a white population. Maybe they work in a white and black population. You get Latinos and Asians. They don't' work and they'll lead you to make wrong decisions. So how do we get patients to manage? Well, it depends on your theoretical model that you're using to look at Latinos and the communities, what do you have to work with. And we do have some things to work with. We've saved a ton of money on heart, cancer, stroke, but there is the issue of diabetes but it's a lot less than heart, cancer, and stroke. We do have issue of obesity and lack of exercise. How do you manage the wellness of a Latino population?

I will submit the theoretical models that we use today in research do not help us because they project illness, dysfunction, and disability. We look at the data. Not only is there something going on as we are responsible for 50 or 100 or 200,000 lives, we need to know, how do we manage the wellness? And as Aida said, what we do know as the risk factor is being born in the United States and that is now driving Latino population growth, it's the births, it's no longer immigration. How do we keep the US born children as healthy as the immigrant parents? That is the key for succeeding under global payments.

So, what we're doing is we're developing metrics at White to truly understand what do we have to work with as White Memorial Medical Center moves toward being part of an ACO and has to survive under global payments. And for some reason they didn't look at the data. They thought they had this huge problem. Now they understand they've got a huge subsidy, they just have to keep that. They can't let it get away. So we're trying to
find metrics that will guide wellness management, not focus only on illness treatment. Stuff that can be done at a local level, at a zip code level, that will be refreshed more often than every 10 years because if you use census data, that's only every 10 years to get enough sample size. In a small area, you're going to need about five or six years’ worth of data. So that's basically what we're looking for. We're trying to create better theoretical models of Latino patients. We need to look at just Latinos not as different, just as Latinos, but what is going on that gives us these outcomes within its own terms. 

I mean, my colleagues in New York are looking at the idea of, they call it the barrio advantage in birth outcomes. Somehow with everything else, if you're a woman giving birth or surviving breast cancer in a barrio, there's a barrio advantage. But what is it? Well, we need to find out. What is in that barrio advantage? As we look, for example, within metrics, they look at food deserts and make pronouncements about food deserts, but guess how a lot of communities get their food, through food stands, food trucks that don't show up on the standard metrics because they don't have a bricks and mortar location. You need to know, I think as everyone as Hector, as Aida, as everyone has said, Greg, you need to know the community and academic research centers do not know that community. We use their measures. We're just going to replicate their vision even though our gut tells us it's a little bit different when you work with Latino communities. So, that is why we're trying to develop metrics to manage wellness, Latino wellness, and I think it has a lot to do also for helping us as we move towards patient-centered research and outcomes. We just need to create our own models.

RECOMMENDATIONS

A. How to Increase Hispanic Patient Engagement for Research

2. Work with media which is very important to recruit Latinos to research.
   a. Message – how it would benefit to get patients engaged – motivational to do better for their health and the health of their families. Learn how to reduce complications of diabetes, for example
   b. Trusted source of media – familiar, ethnic papers, radio
   c. Use of PSAs that are free

3. Community Health Workers and Community Health Clinic Providers
   a. Reach out to Latino groups for Latino participation in PCORI

4. Make sure we ask the right questions; use appropriate metrics
   a. Need to shift medical model of care.

5. Engage community health centers ➔ Organization of community health workers

6. Co-funding community organizations

7. Go back to the theoretical models and recognize that current models do not apply to Latinos.
   a. What one question would work for Latino population? Key: Developing models of well-being/health
   b. Could it be a sense of community?
8. Research needs to be acknowledge diversity in Latino population

9. Go back to square one. Prediction models are incorrect.

10. Language Services –
   a. should be included in the research design from the beginning to reach Spanish speaking patients.
   b. Bilingual teachers in research training needed for Spanish language
   c. One on one learning – personal, grandchildren

B. How to Increase New Hispanic Investigators

1. Develop a Hispanic Research Mentoring Award
   a. Incentivizing (financial) mentors to mentor multiple individuals with accountability methods
2. Need for diverse workforce to perform effective community-based research
3. Develop culturally competent medical training that goes beyond stereotypes of Latino patients.
4. Develop skill-building curriculum for new researchers
   a. community partner research
   b. Systematic outreach
   c. How to mentor Junior Faculty for Senior Faculty
5. Develop standardized curriculum in medical school for a research career track
   a. Community doctors needed to teach about patient’s problems

C. Promising Hispanic Research Needs

1. Community partnerships and sustainability are key

2. Research should include social determinants of health and impact on disease

3. Diabetes patient-centered research with doctors’ referrals to educate patients in self-management, capacity building

4. Dedicate resources to helping young, diverse researchers build their capacity so that they can succeed in the grant process.

5. PCORI Operations and Processes:
   a. PCORI could diversify the reviewers of its applications. There was a strong concern that there were people reviewing proposals involving health equity issues that really did not understand them sufficiently to make good judgments.
   b. Conduct an internal analysis of the application process (including through focus groups) to identify the barriers that researchers from diverse backgrounds (including communities that suffer health disparities) to succeed in the funding process. There was expressed concern that seasoned researchers were being rejected.

6. Research Priorities
a. As an over-arching matter, it is critical that all data looking at racial and ethnic minorities be disaggregated by heritage group particularly for Hispanics, but this is also relevant to APIs. There are distinct cultural and outcome differences between Mexican Americans and Puerto Rican’s, for example. For research to be most useful, it must account for this. In addition, researches want to be able to have data differentiating immigrants vs. US borne, and how many generations in the US.

b. More research on options to address socially determined barriers to improving clinical outcomes is needed, including linking to social services and further research on Promotores and CHWs, especially around the value of race/ethnicity concordance between CHW and client and methods of funding their work.

7. We need to come up with new models that put an emphasis on our culture.

8. Communications with patients should be encouraging – ‘You're going to make it through, but you're going to need to cooperate.’ And make the materials easy enough so that, regardless of literacy rate--and this has nothing to do with intelligence; it's called education--they will be able to comply.

9. Specific conditions:
   - Alzheimer’s
   - Mental & Behavioral health, including depression, PTSD, Substance use
   - Chronic Pain
   - Increased adherence to 3 dose course of HPV vaccination
   - Increased uptake of prostate cancer screening
   - Improving asthma management options for Puerto Ricans, including which medications are more effective (given poorer response to albuterol).

MEETING #2 June 28-29, 2016
Opening Remarks
Elena Rios, MD, MSPH
President, National Hispanic Health Foundation

Welcome to the National Hispanic Health Foundation's second meeting on setting an agenda for Hispanic patient-engaged health research. We had over a hundred people interested in this topic and in helping us develop an agenda. I understand you have a pre-survey also that we are collecting.

I would like to thank the Patient Centered Outcomes Research Institute, (PCORI) for their support of this project. As you know, PCORI is very data driven. We are interested in getting as many different ideas from your own experience as possible. What we said we would do, the project aims are to facilitate the expansion of patient centered outcomes research with PCORI by developing a Hispanic patient-centered research agenda, building the skill and capacity of Hispanic serving physicians, researchers, and Hispanic patients themselves to conduct patient centered research by learning from all of you, and influencing Hispanic focused health researchers to utilize more patient centered approaches in their research. Again, I’m going to clarify that we are here to develop an agenda about the community, about the patients. Our goal as an organization is to improve the health of Hispanics and other under-served through research training and other activities with the Hispanic and non-Hispanic research community.

We want to set an agenda so that everybody that applies to PCORI and other
research agencies can start thinking about the importance of including major efforts at different levels whether it's inviting the patients, whether it's inviting the stakeholders like clinics and hospitals and other clinicians—nurses, social workers. We're going to be working in a clinician team in the future.

Also, not only recruiting but designing your research and disseminating the research and that we disseminate it so that it reaches back into the community and through our radio stations, through our ethnic newspapers. We have to think about our responsibility in putting together a report that PCORI will take back to everybody that applies for research to add the Hispanic focus. That's what this is all about.

In terms of what we are here to do, we are going to hear from speakers who are expert in Hispanic health research and from the patient and a patient advocate from one of the local community clinics, Mary's Center to discuss their experience in Hispanic patient—engaged research. We are also going to have four different working group sessions. We're very interested in your top priority methods or strategies that you have done as researchers or you would like to see as a Latino involved in academia. The first session will discuss what has worked for Hispanic research from your own experience. The second session will focus on research strategies that facilitate working with Hispanic patients. The third session will focus on training strategies focused on young faculty that are interdisciplinary, PhD core competencies, or physicians, undergraduate and medical students, and administrators. The fourth session will focus on mentoring strategies for physicians, faculty, and mentoring strategies in research, in general.

One last thing I wanted to highlight is about the readings from PCORI about patient engagement or about Hispanic research and from our literature search from Pub Med that have to do with cultural competence and Hispanics, and on Hispanic health research studies. We recognize that PCORI has awarded some research on Hispanic patients. But we need to push the agenda to have more funding being targeted to those who care about our community and to increase those who understand the importance of our community as the largest ethnic group in the country.

Some of the examples from the PCORI articles—and I'm just going to read just a couple things—of lessons learned from their slide presentations. One, ask first, exclude second. The more the better. The more Latinos, the better. Think in terms of a Latino lens. Financial compensation is critical. Three, training, training, training. Four, only ask for input if input will be considered. Don't waste our time. Number five, our richest resource is our own portfolio. Build on your strengths. Build on what you know. We need all kinds of facets about our community whether it's children's health or women's health or diabetes or whatever the case may be in your research. Flexibility is key. Focus on the unusual suspects. Engage patients in your studies—for example, in identifying research topics, developing the research question, proposal development, developing budgets, identifying more people to the team and study design. These are processes that you're well-aware of are part of research, but at every step of the way how do you involve the community and patients? It might be that the target is based from a community clinic as we are going to hear about. Clinic research advocates have a sense of what's needed to be involved.

Another article talked about the importance of advice for future stakeholders. We must look forward and recognize there is a critical need for training Hispanic researchers as well as for training about Hispanic health research. Many of the research projects that are awarded by the federal government or by PCORI seem to go to the most experienced researchers. How are we ever going to develop the people to replace us if we don't include the next generation? There's a real need to start thinking about how you can involve training mechanisms of young researchers within your research studies. Patients' views can also improve clinical trials for the participants. If you're doing research on clinical trials,
think about what and how you could actually talk to patients before you do clinical trials.

Then there was a list in table three in one article. I'm not going to read it, but it's patient and stakeholder engagement in the PCORI pilot projects description and lessons learned from 2015. It summarizes early lessons learned about the importance of adaption and continuously involving stakeholders and defining expectations and roles and really thinking about how you work with others. It's not just about you and your research team. That's the whole point.

Lastly, there is an article about cultural competence. It includes a table with three circles or priorities or the major factors involved in being culturally competent. On this slide it talks about patient centered care. This article is actually talking about the symbiosis between care and cultural competence. If you replace the word “services” with research and you had these same research protocols or processes, every stage of research, how could you combine it with cultural competence? At every stage there would be an intersection of thought. For example, research aligned to meet the patient needs and preferences, healthcare facilities convenient to the community where you do the research, documents tailored to the patient needs—literacy, language—and data on the performance, data on the research, available back to the consumers so that we can help our communities. With that, I want to thank you for being here and bring up our Moderator, Dr. Jose Pagan.

José Pagan, PhD
Director, Center for Health Innovation,
New York Academy of Medicine

You know, there's something in common that binds us is our interest in Hispanic patient centered research, Hispanic research. You always have this feeling that probably in your organization like you may be one or two people interested in a topic like this. What we're trying to accomplish with this is basically bring together all of you to have that experience of basically collecting all that knowledge that you have of things that you have experienced, for example, on how to do research, how to mentor faculty, how to help students be interested in Hispanic health research. Also, things that you wish existed when you were going through that process. I mean many of you had a similar experience to me. I went to a university in south Texas that has some resources, but I wish there were more resources that allow me to do the work that I wanted to do that mattered to the community. It is exciting to see all of you here.

One thing that struck me about the reception we had yesterday, and I wish all of you were there, was the level of diversity that was there in terms of not only how diverse the Hispanic community is but more than anything the number of fields involved and so on and the level of interest of people coming from law, medicine, public health and so on that I think a forum like this allows us to focus on. Before I introduce our panel of speakers in a few minutes, I wanted to add to what Elena said on basically help you think about—when you think about something that is patient centered, a program that you're implementing going beyond not just designing something that takes into account what people want and need but also thinking about who is going to pick that up so that it is adopted.

I know that many of you have developed strategies to, for example, help people manage diabetes, do prevention work and so on. Then many of those initiatives basically—you wonder why people don't adopt them. I'm a health economist. I do a lot of work around that, and I just wanted to talk a little bit about that before we get started.

A couple of points. What I want to talk to you about briefly is how do you align evidence for action to improve Hispanic health. The first point that I wanted to make is something that you have seen. The AHRQ has 175 slides on Hispanic health and issues like that, but the main one that I—the most interesting one that I find is this one. If you
look at the Hispanic population projections by 2016, the Hispanic population is going to go from 17% to 28%. It's going to be as high as 33%, a third, for basically kids, anybody under 18. What's happening is basically you have healthcare delivery systems that now need all of you to be able to develop programs for this growing population.

A second point that I wanted to make was that if you go back to this 175 slides that I told you about one thing that you'll see is that what they did is they looked at what has happened over the last ten years up to 2012, so ten years back before then in terms of movement or changes in disparities. One that struck me that I thought was quite interesting is they looked at different measures of access to care, access measures. If you look at the difference between Hispanics and whites, just to give you an example—or differences, actually, across ethnic groups, you see that the one that—where many of these access measures have gotten worse is for Hispanics, 14, which is about 65% of all the measures that they looked at. You basically have—so although you see improvements in health insurance coverage and so on, there are some issues connected to access measures.

What I wanted you to think about is as you think about the patient centered programs that you develop think about the following. The way healthcare reform happens is we were focused on health insurance coverage mostly. People were concerned about cost and so on. You hear of this thing called a triple aim, right? Basically, improving population health, the patient experience, and reducing costs. Everything has basically boiled down to basically cost, the cost side of things. By that I don't mean that everything is about cost but I mean that if you keep quality constant then people are going to love whatever you come up with that can reduce cost. That's the point that I'm trying to make. Part of it is because it's very hard to change prices. People will go after you if you try to change the prices of healthcare services.

What's going on in the healthcare system is instead of focusing on delivering a specific service you think about the total cost of something. Then you try to cut the cost on that. How does a health system or a health plan look at the world? This is a report that I saw that their CEO gave a talk on in Houston last year. If you look at somebody with two chronic conditions, you know, the cost to the health plan is about $12,000 per year.

Basically, what everybody is trying to do is gain transparency on where that money is going. What do you see there? You know, some people see a hat, right? It could be --. You're trying to gain full visibility of the population that you're serving. This is happening with the health system, but it's also happening with the payer. That's where we come in. We know what's going on in the community. We know how to change behaviors. We know that populations are unique. All I'm trying to do is encourage you to think about the programs and the approaches you use and also think about that extra step. How do you show the case for the work you're doing so that it actually has a chance of being implemented and people don't just say oh great you improved some health outcomes? Is it going to really change that 12,000 dollars that I have to worry about?

The way many systems are doing this is they're trying to understand, for example, the footprint in which they operate. You probably have seen this in your community. Because now you make money based on the average cost of care, you need to understand that footprint. That means understanding where every penny is spent on that person. If you don't, then you may actually lose money. What that means is that when you think about the programs that you develop, things that can matter to people, you have to think about cost but you also have to think about quality and so on because, for example, some health plans may not be interested in cost. They may be interested in quality ratings.

We have a project, for example, at Mount Sinai where we're looking at reducing disparities in post-partum care. We're working with a health plan that is really interested in quality metrics more than cost. You have to be aware of that. Then the timeframe. Most of our work when you look at the timeframe on benefits and cost they happen way
into the future. A foot amputation happens ten years out - how do you take that into account? Understanding the population effects over time is also important.

Then, you know, you develop something - the likelihood that it will get adopted will depend on a lot of trial and error, which is something that you want to be able to do. When CMS, for example, looks at what you're doing they're going to be looking at factors like that. I'll just give you an example here from the population of San Antonio on a project we're working on with the health department. I'll just show you an example of some of the work we've done, which is basically this is what if you take everybody in San Antonio that has prediabetes and diabetes and then look at what happens to that adult population over time. For example, the number of people that would have heart attacks would be about 24% of that population will have a heart attack, an MI. Fifteen percent will go blind.

What happens to that population if you reduce A1C by one point? Well, you'll see these changes in each of those outcomes. You can even look at cost effects at the bottom here. The point that I'm trying to make is that I can tell you how to do this with the fancy modeling we do, computer modeling we do, but we need folks to be working hard on how you implement things that would actually reduce that A1C by one point. They have to be culturally based. They have to be tailored towards specific communities and so on. Otherwise, this data is just basically an academic exercise, and that's basically it. That's all I have to say on that.

**Hispanic Health Research Recruitment of Patients**
Aida Luz Giachello, PhD
Professor, Department of Preventive Medicine
Feinberg School of Medicine, Northwestern University

The objective is to summarize some of the research recommendations and to be able to share some of the challenges involving the inclusion of Hispanic Latino in clinical research and be able to also discuss about some of my research priorities.

Now, obviously, we all know the importance of focusing on Hispanic Latino health. Already Jose was able to share the population growth. I just want to highlight again that in July 2013 Hispanics represented 17% of the U.S. population. The Hispanic Latino population is growing at two percent rate annually, so there's about 1.1 million Latinos that are added to the U.S. population every year. By 2060 Hispanic Latino would increase to 128 million from the 54 million that we have right now, one out of three Americans will be of Hispanic Latino origin, and the United States will be the second largest Spanish speaking country in the world. Mexico City being number one with 128 million.

Why focus on Latino? Well, we know that there's an increased recognition that Hispanic Latino is an important sector in the U.S. society. For example, the Latinos are essential into the U.S. business with Latino purchasing power increased to nearly $1.5 trillion in 2010. In politics, we recognize how critical the Latino vote is for successful campaigns.

In terms of the Hispanic patient-centered outcome research agenda, first it's important to clearly realize that we must focus on the health and medical process. The patient centered outcome research agenda is really trying to determine what happens with Latinos when they enter the medical care system. Unfortunately, issues of access to care, issues about social determinants have to do with the environment. Those are not necessarily included in that agenda.

The interest is what happens to Latinos when they enter the healthcare system. How are they greeted? What is the patient, doctor, nurse communication in relationship? Do
they take into account literacy, language, culture, which are many of the issues that we've been discussing all along? What is the end result of the health and medical care in terms of outcome? The great emphasis is really what happens with medical intervention—to what degree the patient is better off as a result of an intervention that the healthcare system has been providing. What is the effect of health and medical care intervention in terms of the Hispanic patient population? Medical intervention can be viewed as being very successful from a medical perspective or the technology that is being used. In terms of the outcome, the Latino may be suffering for the rest of their life in terms of pain and other discomfort.

In terms of outcome from the patient perspective this was not necessarily a very good intervention. The research agenda in patient-centered outcome is assessing the specific diagnostic—the preventive and treatment strategy. That is very critical. What is really being done to our Latino patient when they go into the healthcare system? What are new methods to evaluate care? How are we evaluating the e-medical chart that is being used? How is that all included and improving the outcome? What is the assessment for the new medical psychosocial communications? You know with the medical information technology now you're using the smartphone often to provide counseling or to inform the patient about their next appointment. We need to know. I mean there's no research when you really look at all those many new interventions. There's no research that really tell us where Latinos are being benefitted, to what degree that is relevant and appropriate. If it is so, then to what Latino subgroup may benefit from some of the many medical interventions and methodologies that are currently being assessed.

Assessment of patient provider relationship including communication is another research issue of importance. This is a very huge issue for us Latinos because we know cultural barriers and linguistic barriers that Latinos experience. All that needs to be factored in when we develop a patient-centered outcome research agenda to improve the dissemination of information. How can that information be able to improve clinical practice, developmental policy, program planning, etc.? What has happened—and all of you are aware—that a researcher published a wonderful manuscript journal article - - the community benefit. The community leaders are anxious for that information so they would be able to mobilize and engage in policy development so they could improve the wellbeing of the community. Then the information is also valuable for them to write a proposal and be able to articulate the many issues that are being confronted by the community.

Patient-centered outcomes—ultimate result is to improve the medical treatment effectiveness. This is only happening when you compare different modality or patient care. They're also interested about the efficiency of the healthcare delivery system, how it's going to reduce the high costs of medical care while improving the health medical and quality of life of individuals. Key is the concept of quality of life, the capacity to facilitate the individuals to function at the highest possible physical, emotional, and social level. I wanted to mention here that for Latinos the whole issue of health equity and social justice needs to be integrated in whatever we do with PCOR. This is critical because there has been already research that clearly indicates what the Institute of Medicine landmark report in 2002, Equal Treatment, found - confronting racial and ethnic disparity in healthcare, which is the title. The report concluded that racial and ethnic minority and women as a group were not getting the best quality of care—that there was already embedded into the system a whole series of biases, prejudices, and that that affects the kinds of care, medication, and procedures that are being done on Latinos. We should be able to engage with patients to figure out what is really happening because we know that although this report was done in 2002 we know that currently that is still a problem. The Latino is not getting the best quality of care when they enter the medical care system. We need to figure out ways to provide the documentation, to provide the evidence, to be able to compare how well they're doing relative to white and other populations.
According to Ron Anderson in 1995 in an article that he wrote he said that we learn through competitive research. When you talk about PCOR you are actually talking about comparison research. We learn from Hispanic Latino versus majority. That's why we always need to have a comparison group when we are looking at research in general. We also look at Hispanic Latino versus other minorities—how well we're doing when we are examining the health and the delivery of services to other minorities. Then, specifically, in terms of Latino we want to know how well Puerto Ricans are doing versus Mexican American or Central and South America. The Hispanic Community Health Study study of Latinos were able to provide a tremendous amount of evidence based on a large sample size, over 16,000. They really provided the evidence of the differences in health status in access to care and many other indicators among the many Latino groups. That should provide a lot of the information that you may need to find out if your community are serving primarily Central and South America what are the issues that those communities have. How can we be able to make sure that when they enter the healthcare system those issues are addressed appropriately.

Anderson also said Hispanic Latino studies are legitimate if the problem has not been sufficiently studied in any population or the problem has not been sufficiently studied in the Latino population or the nature of the problem appears to be different in the Latino population. You need to keep those perspectives in mind when you develop your research agenda and when you think about what should be the research priorities for Latinos.

The reason that I got involved with outcome research was actually in 1991 when the Agency for Healthcare Policy Research, which changed their name afterward, launched an initiative in response to congressional mandates. At that time they provided funding to establish 11 - - medical center effectiveness program across the United States. I was able to receive funding at the University of Illinois to establish in 1993 a - - from that institution. That's where at that time most of my effort was more addressing access to care, which is critical and still is an important issue—and addressing environmental condition. In reality, the focus really pushed me to focus about what really happened with Latinos when they enter the medical care system, when they go to the Chicago Department of Health public clinic or they go to a - - qualified clinic. It really push about what happens to the Latino.

There were very few efforts at that time focusing on outcome research, so the Agency for Healthcare Policy were able to match us with other senior investigators because we proposed a developing center as we didn't have in-house at the University of Illinois the kind of capacity to be able to do research at a level that was expected. So they matched us with a number of other senior researchers in the area for us to be able to launch this particular effort as it relates to Latino health. Most of our efforts were primarily engaging in hypertension, asthma, - - health and many others. - -, who is here, she was one of our consultants for the center and many others. In reality, what we needed to do at that time, and it still seems to be the agenda today, is to say what works and does not work once the patient enters the healthcare system and to increase the body of scientific research of medical treatment effectiveness and to train minority and non-minority investigators because most of the research in this country in our community are done by non-minority because we don't have the - - minority investigators.

Therefore, we have a responsibility to educate them in the process on how to engage in research using culturally and linguistic appropriate approaches. During that process I started developing community-based participatory research. They were directly or indirectly affected by the problem. Engaging the community provider so they could be able to define the research agenda. Mobilizing the community for action so the research result will be used for policy and program planning. As a result from that effort, I was already engaged in what is called now community based participatory research. The term did not
exist at that time when I started doing. The reason I started doing is because one of my backgrounds—I have a master's degree in social work, and my other degree, my PhD is in sociology. I already knew about strategy or community mobilization and how critical it was to mobilize the community and empower the community around health. That's how I begun to engage in this kind of field that I have continued.

Saying that, what are some of the research agenda? Well, first of all, I think that one of the things that we haven't done enough is to really look at the second and third generation and on of Hispanic Latino. A lot of focus, a lot of discussion for the right reason, and I support them, is the undocumented and the recent arrival. That should continue, but if you look at the research data—if you look at the published articles that are emerging, it clearly indicated that second and third generation are the ones that are at higher risk of teen pregnancy, alcohol, drug addiction, school dropout rate, teen pregnancy. I mean the list goes on and on and on and on.

I think that there has to be a way of thinking about how can we be able to focus on the second and third generation that are in so much high risk. There could be many explanations for that. Some of the explanations could be that the immigrant parents are so involved in one or two or three jobs day and night trying to make sure that the food gets on the table and support the family that maybe in the process they're not able to provide equally - - attention to the children. Then with the gang related activities in those communities where many of them concentrate then they get into becoming members of those gangs. As a result, we lose them in many different ways. There has to be a way in examining the needs of those particular populations together again with the immigrants and recent arrivals and undocumented. We need to somehow focus attention to that second generation.

The other thing in terms of the research agenda is, again, looking at the leading causes of death and disability. Cancer is the number one cause of death for Latinos. Cardiovascular still is number one for the rest of the country, but for us it's cancer. Anyway, regardless of whether it's cancer or heart disease we need to figure out... I mean, you know, when you were born your heart is healthy. Something happens along the line that our heart and many other related conditions develop. We need to find out if we're taking our children to a wellness program and we ourselves are engaged in many other wellness activity that is now the mode and the push what is it that the healthcare systems are not able to influence or be able to intervene effectively in helping us as we are engaged in or developing risk factors. Those factors that are being developed are not given the same attention as to when you actually develop the chronic disease, from my perspective.

There has to be some way in that research agenda to think about why the healthcare system is failing us and is failing the whole community for that matter. We know that the lifestyle behavior and the environment and modifiable risk factors such as smoking, obesity, physical inactivity, high blood pressure, etc. develop and are influenced by many different component. There has to be a way to assess and hold accountable the healthcare system as we interact - -. PCORI is needed to determine medical intervention and effectiveness for early prevention, diagnostic treatment and survivorship. Most of the effort is around more treatment modality examining that. We need to know about prevention. What can we do to be able to prevent some of those development of risk factor before they happen?

We also need to know what the healthcare system is doing in terms of primary prevention, which is designed to modify adverse level of risk factor once they are present to avoid an initial cardiovascular event, for example. The Hispanic Community Health Study of Latino had documented a high degree of anxiety and panic attacks. One of the research agenda should be mental health. We need to do more studies. I know that PCORI have already developed some agenda in that area, but it's not as specific to Latino to the
degree that it should be. The data that is emerging is the high depression from the Hispanic Community Health Study that exists in our community. The high use of alcohol and drug addiction that we also knew from other studies. We need to assess the impact of information technology. Like I said, use of the smartphones to provide counseling, appointment and referral, etc. etc. We need to assess the quality of mental health services.

In this outcome research priority the assessment of what is really happening through the healthcare system in the mental health delivery system needs to equally be assessed. An area that I'm working more recently is tobacco use. I mean cigarette smoking, as you know, with the whole tobacco settlement agreement cigarette smoking was able to drop to the point that about 18% of the U.S. population smoke in general. When you look at the data for Puerto Rican, it's 35%. When you look at the data for Cubans, it's about 32 or 33% according to the study. When you look at data for Central and South America—actually, Dominican, I think, is about 11%. In reality, we have this diversity of prevalence of, in this case, cigarette smoking. In addition to that, you know, some of the studies that I'm doing is really indicating that this whole area of using vaping devices is reaching an alarming proportion. I mean the high use of hookah, electronic cigarettes. Right now, the Food and Drug Administration cannot be able to regulate to the degree that they can those products because the science is not behind. We don't know yet the effect of many of these emerging devices. We don't know yet the harm to their health.

Another research is HIV AIDS. HIV AIDS, you know, we still represent close to 20% of all the cases. Thanks to medication and new improvement, the survivorship is much longer. We have improved the quality of life of people with HIV AIDS, but still there's a lot of information that we need to gather, that we need to assess because we don't know yet to what degree Latinos are doing better off compared to African American and white in terms of the medical treatment, in terms of the medications that are provided. As we know, providers tend to provide the less costly medication, although they may not be necessarily the most effective. We need to know more about the care coordination that needs to take place, how medication or adhering to medication is happening in our community.

The Hispanic Community Health Study clearly documented that Puerto Ricans are worse off in many indicators that were studied related to cardiovascular diseases. We need to start, you know, telling the PCORI that they need to develop an agenda that would allow us to really assess the interventions because Puerto Rico, for example, they're a U.S. citizen by birth. They have access to care because they usually are covered through Medicaid or Medicare. They should be able to get the quality of care that they deserve, but that's not what the case—what the data is showing us.

Other priority is looking at women. You know, women, as we know, live longer than men. The data indicate that they tend to live in long-term care facility below poverty level in poor quality of life. They are three times more likely to live with conditions that involve the medical care system and how responsive they are to the needs of women. For that matter, the older adult. One of the areas of concern is Alzheimer's disease which affects Latinos with high rates. We really need to figure out what the medical care system is doing for us once we start interacting with it. How soon do they diagnose the condition properly? How soon are they able to provide the benefit of the many emerging medications and drugs? What is the kind of support system that we have for the family who are really taking care of the loved one? The care coordination model needs to be assessed and evaluated to make sure they're culturally appropriate. The medication side effects—that includes, you know, some of the many new medications, to what degree they're involved in clinical trial.

The Hispanic Community Health Study focuses on more data on diabetes. We need to know—is everybody getting metformin, for example, for prevention?
In terms of PCORI’s processes have limitations. Number one is when you submit your letter of intent to PCORI you need to have a nearly complete proposal because they ask for hypotheses, research models and design, and the partners. In other words, although they give you a month to respond after submitting the letter of intent, you need to start developing relationships with the health facilities or organizations/coalitions to work with patients. I usually start the process by meeting with the clinics that I want to partner with. What are your priorities? Because in the PCORI it's about the priorities of the healthcare providers and the patient. How can we schedule a roundtable discussion, a focus group or other meetings with the patients, so they can tell us what are their concerns in the given community in getting access to interventions.

You have to begin your agenda in developing your proposal from the provider and the patient perspective. All the other partners—remember PCORI because it's competitive research you have to have different arms where you are comparing the state of the art of whatever the issue you're proposing with whatever new interventional modality. You really have to have a pretty much defined agenda. One of the limitations with PCORI, like I mentioned before, is that you cannot really engage in the social determinants of health and find out how the work environment, the school environment, the home environment all that impact because in reality this research is a clinical study. One of the things that we could propose is how can the clinical research agenda be expanded so that it includes some of the social determinants that affect the health of our community. How can we get PCORI to establish an initiative, you know, a center grant announcement like the Agency for Healthcare Policy and Research developed in 1991 where there could be centers established across the nation—that Latinos are running to integrate the research with the training and the policy component and be able to engage the community and empower them in the process through capacity building to the degree possible?

Greg Talavera, MD.
Professor, Public health,
San Diego State University Graduate School of Public Health

My name is Greg Talavera, and I'm a professor at the Graduate School of Public Health at San Diego State University but I started my career as an ambulatory physician in a large community health center on the border between Mexico and San Diego. From there I got my understanding of the community and my beginnings for my research ideas. In my career, my agenda has been the clinic's research agenda. I've only researched things that were relevant to the community and relevant to the needs of the organization. It's been easy for me to define what to go after and what to do because in essence that's community based participatory research. You're not going in and telling them that you're interested in things that are not relevant to them like Kawasaki's disease or really rare diseases.

I've been researching with them the high volume, the high need issues such as cancer screening and detection, cardiovascular disease, diabetes, and various other things—smoking cessation in Spanish and so forth. My world is really made up now—I started with them in the first ten years of my clinical career, but fortunately, unfortunately, about ten years into it they got a really bad administrator. I get invited to join academia about practicing medicine, and I kind of liked it. It was kind of nice being able to attend my children's events at school and not have to rush to clinic and be on time for patient care and things like that. Fortunately, I've been able to balance the two together now.

The clinic I work with is called San Isidro Health Center, and they were started in 1969 under the OEO funding that was happening during the social political revolution of
the time. They grew from a small little trailer to now 17 clinics and 90,000 registered patients, 95% Spanish speaking. They're a really good laboratory, and it's a really fun place to work. I took a position in the school of public health, as I mentioned, and I've been able to marry those two together as well as involve my high powered ivory tower colleagues up at the University of California San Diego.

San Diego State is primarily a teaching institution, but they do have a research arm and they've done quite well. In fact, if they were at UC they would probably be in terms of funding levels in the middle of the UC system, so they've done pretty well for a charter that was originally started for teaching. About ten years ago I started through funding from the National Institute for Minority and Health Disparities, a center of excellence, which they now call the South Bay Latino Research Center.

I'm just going to drill down to the model—well, the patient centered model that PCORI would call patient centered medical home but something I've been doing for about 15 years, which is working with clinics and listening to what they need, developing the models that work in their economic environment because they are unique. As federally qualified community health centers they work on a reimbursement mechanism that's called prospective payment. Very different from fee for service. Very different from capitation. It's essential that someone understand the environment that you're working in, the economic environment, so you can design your studies in a way that is sustainable and replicable to them as well as all the community health centers around the United States.

As I mentioned, the model is really based on community based participatory research. For reasons that I've just mentioned, I really think it's true participatory research because they have their own research center. They have their own mechanism for approving these grants, and they have significant input because I used to work there and have helped them out in numerous occasions by filling in as an acting medical director. I really understand what they're going through. It's really, really been a great organization to work with and a great experience.

I really wanted to focus on the model, the PCORI model that I think is really important. I found this slide last night, and I thought it would be useful framework for our discussions at the roundtable. In public health we use the social ecological model to look at health disparities, but I was thinking that this model might work for us today thinking about the social ecological model for researchers going from the individual level to policy level. I'll throw that out there for your consideration.

My strategy is to be place based. As I mentioned, I work with the community health center. They've been fortunate to grow in their sophistication of research and understanding and appreciation of that. They realize the importance of research. They have an infrastructure. As I mentioned, they have their own research department with on staff promotoras and on staff researchers now. The theme of our work has always been mutually beneficial projects. Whenever I bring something of my own interest to them or from outside researchers the bottom line they understand. They always ask what's in it for us. A lot of things get denied because there is nothing in it for them. They don't see any potential. It's not what they want. It doesn't help them address their needs. Recognizing that over many years, I usually bring them things that they want or convince them that's what they want.

It's also been an environment for doing training. Training grants I think are something we should talk about. It's a model that exists in NIH, and maybe PCORI can pick it up. - - many of you know is a cancer collaboration that's existed for about 20 years under the direction of - - out of San Antonio, Texas. That's another idea I wanted to put out there. In terms of training clinicians, one of the things that I really think has helped my career is working in an integrated research unit. It's hard for young faculty joining academia in departments where research may not be strong or research collaboration may
not be strong to launch their careers and be successful in their trajectory unless they're surrounded by multidisciplinary teams. I was fortunate to have that environment. I was working with clinical psychologists and behavioral scientists, and I was a physician. Together we capitalized on our strengths and wrote grants. Sometimes I would be PI. Sometimes others.

I think without that, that kind of environment, it takes a long time for the individual to blossom on their own. Maybe even with just, you know, a 10,000 dollar startup grant or something like that. You really need to be in an environment where the spectrum of research experience goes from junior to senior and it's multidisciplinary. That's one thing I wanted to put out there. Then, of course, your research environment. Are you in a university that supports research versus one that expects it and demands it at a high level and so forth? Some thoughts.

Very quickly, getting to my center, South Bay Latino Research Center. It sits—this is where we are right now. We're in the middle of the heart of the South Bay area San Diego where the majority of the Latino community lives and exists even before it became the United States. We have about 18,000 square feet and about seven to ten projects at one time. Our landmark study is the Hispanic Community Health Study, so that drives a lot of the resources and expertise that we have. I've been able to bring researchers and resources from San Diego State, combine them with San Isidro Health Center, and over time we hit on this unique idea which I call the partnership clinic. The university pays for the facility, rents it. It staffs it with telecommunications and networking services and so forth.

The clinic decided during my research time that I was bugging them too much, so they said why don't we make your clinic a satellite clinic of San Isidro Health Center. We are a federally qualified community health center in the middle of a research center now, and it allows us to have total control over what we're doing. I've now gotten out of their hair, and I only bug them at their productivity level, you know, because they're very dependent on productivity.

This is the model that I developed about ten years ago that has gotten—been successful in terms of getting a lot of grants when we describe this. It's a true partnership, and I think it's really kind of what PCORI is looking for. It's a great idea designating a research center as a satellite facility of a community health center because we have electronic health record there. We have through business agreements our staff—both research staff and San Isidro staff we can recruit from their EHR. It's a great laboratory for conducting this kind of research.

This just shows you the replicability of the study. These are all the community health centers in San Diego—so models that we develop in our site at the center can be replicated in other facilities. This is where we're located. We're right here next to a major hospital, community hospital. These red dots represent the community health centers that San Isidro runs. They have about 17—90,000 registered patients. We're about to recruit diabetics, people for cancer screening. Next week, we're hoping to talk with the precision medicine group about funding us to do some pilot work in precision medicine. We'll be able to use the same infrastructure, same staff, same recruiting mechanisms to bring people in and study how precision medicine could be accomplished in a community health center this way.

We've done this with obesity, diabetes, cancer prevention and control. It's just a great, great relationship. The other good part about it is I get to see patients there too right in the middle of my clinic. It's been a really good experience so far, and I really think it's a replicable model that occur through other universities and so forth. I need to wrap it up. I was just given the noose. I can talk a little bit about these things around the table.

Just to sum it up, I think the key features of this model of patient centered medical home is good because we have colocation of services. We use - - let me just go to the
diagram. This is the study we're currently doing, but this is the patient in the middle. We're targeting their self-management goals for diabetes. In this same clinic facility they see a specially trained physician, which is me, trained in behavioral medicine. We have a mental health or behavioral health consultant. We have group led promotora classes, which talk about diabetes, and we have a care coordinator. This is really the model that everybody is looking for, but we have the research money to accomplish it at a high level.

We're following the ARC guidelines for highly integrated services, so when I see the patient first I walk the patient over to the behavioral health consultant. I talk about the clinical dimensions of what I found, the risk factors. Then she or he goes into a psychosocial assessment. Then we debrief afterwards and help the patient set patient centered goals for their healthcare condition and traditional promotora led peer health education.

I think I'll stop there, and I look forward to working with you guys in the working groups. Thank you.

Alis Marachelian  
Senior Director of Health Promotion  
Mary’s Center

I'll start, Dr. Elliott, and then Dr. Sandoval. So just to tell you a little bit about Mary's Center. We are a federally qualified health center - - some familiar faces here. We were founded in 1988, and we are centered in Washington D.C. and Maryland. We have two clinical sites, soon to be three, in D.C. and two in Maryland. Our mission is to build better futures through the provision of social, medical and educational resources to our community regardless of the ability to pay in a very community collaborative culturally mindful way.

We are here to talk to you a little bit about the creation of our research review committee and why we did it. We started this in October 2014 because we were having a lot of miscommunication within our center, some staff running some research that nobody knew about, researchers coming in and linking up with some clinicians, some social service staff and doing their own research in silos. None of us were getting results. Papers were being published with Mary's Center's name unbeknownst to us. Us finding in the literature, oh look, somebody from Mary's Center said that.

We decided to centralize everything into a research review committee that's composed of our medical team, nursing, health promotion, social services, mental health, finance and our grants department. Those are our major Mary's Center departments. We also have our dental team come in when there's dental oral health issues that are being presented. The types of—we meet twice a month, and we receive—if we can just go up a little bit... How do we scroll down here? All right, there.

We have posted on our website how to apply, and we have an application form, very straightforward, tell us what you're doing, what do you want to do. We'll give them an audience within our research review. Twice a month we meet. We look at this criteria of determining who gets in and who does not. We look at has IRB been approved. Is this going—does this resonate? Is this aligned with our mission, our vision? Do we like this? Would participants, would the patients that we know dearly that we talk to every day, would they be even interested in this? How will this impact both the center, the patients, the future of Mary's Center really? How will this inform our programs to improve them, to improve the quality and the quantity of our participants?

Some types of research that we've entertained have been academic based through NIH. They've been through research institutes like the Urban Institute, some CDC. We have protocol testing for our mental health department. For example, their latest one is
STAR therapy protocol that we looked at of PTSD, post-traumatic stress disorder, among our Latino community. Testing specific protocols on how to do specific type of therapies. We've done clinical trials, which I'm going to pass to Dr. Elliott later and Dr. Sandoval to speak on. To date, we have reviewed since October 2014 42 research proposals. We've accepted 26. Eleven have ended already, so they've gone through the whole lifetime of it. There are 16 that are still remaining. They're ongoing at Mary's Center.

We have student projects. Many come to do their master's or doctorate thesis at Mary's Center as part of our public health teaching institute. Yeah, so how do we engage the population? What would be—what can we speak from the community perspective about engagement? Number one is trust. Establishing that trust, that credibility is important. Hence, having a research review committee so that we can tell our participants, you know what, a whole committee of your team actually looked at this before it came to you. It said, you know what, this is sound. You can trust it. We keep monitoring it. We do a mid-level and a final presentation request from the researcher, so we get the results. Finally, we get the information we need.

Let's see. Involving the participants from the inception, from the beginning is key as well. Getting their perspective. Would this work? Would you be interested? Would your family members be interested in something like this? Getting that pre sort of work done. Sometimes we jump in, you know, when there's a nice beautiful research grant and we don't look at that - - work. That's going to be important to determine later the participation that's needed.

It's also important to use the results prior to engaging in research. Also, involving the staff that are going to be affected by the research in the actual advising committee as well is important to us. The financial involvement, right? It's staff time. It's patient time. It's space that's needed at the centers. That needs to come along with, equitably, with the actual research. I'm going to pass it on now—and if you have any questions let us know—to my colleague, Dr. Elliott, to talk about a little bit on the medical perspective.

Tollie Elliott, MD.
Chief Medical Officer, Mary’s Center

Good morning, everyone. My name is Tollie Elliott. I'm from the D.C. area. The first two presentations were awesome. Very good. Very detailed. There's not much more I can add to that, but what I will say is that they were extremely relevant to me. Dr. Talavera's almost—it feels like my birth twin because I too was in clinical for ten years. I was an OB/GYN. I delivered Mary's Center patients long before I came to Mary's Center. My wife was Puerto Rican, so this is both relevant to me in terms of my children and in terms of myself as well. Certainly, you know, as an African American we've had a long disparity in terms of research and a long disparity in terms of developing trust with research. I take that extremely personal, especially when you look at the Tuskegee experiment, when you look at the experiment that happened down in Guatemala. We're looking at things that are highly relevant towards our community and actually breaking down the barriers of trust, as Alis had mentioned to you, to make sure that people actually want to engage in these kind of research opportunities.

Certainly, as a physician I also have to embrace the mission of Mary's Center's social change model with educational academic, the social determinants of health and the medical. I have to look at that whole spectrum. When we look at the research - - committee—you know, certainly when I get involved I deal with individuals such as, like Dr. Sandoval will speak momentarily, I have to find out whether or not these things are relevant to the community which I serve, which is 77% Latino. I have to find out whether
or not this makes sense in terms of productivity. Does it have an impact on the services that we provide? I know that every time I take a provider out of that rotation it takes away from the type of services that we can give to the community because ultimately it's the sustainability of the organization.

I think the best way I can do this is just to give a testimony and have Dr. Sandoval present his insight and his input and his experience in working with Mary's Center and have some patient testimony as well.

**Fabian Sandoval, MD**  
Ceo, Medical Director  
Emerson Clinical Research Institute

One of the key lessons learned from a patient's perspective is there's actually a summary in Research America that said the majority of patients get their information from the provider. In their case, they were able to access and get information about the clinical research study from their provider who said this is all I can do for you right now. This is what we're doing that might help—in her case, high cholesterol. These are the medications that we have to offer you. We are also conducting a study in your particular condition that might help you. If you would like to learn more, then here's the study coordinators. We had a little discussion earlier. Here's the study coordinator. Here is her phone number. I'm going to let them know that you're interested, and they're going to follow up with you. That's how they were able to find out about it.

Some of the—what was something negative regarding the study was some of the side effects. Some of the side effects were a little bit harsher, but once they knew which side effects they were having they took appropriate measures for over the counter treatment. They felt fine, and so far they're doing well. They were both concerned about the fact that people always say well these research studies are being conducted in rats, right? They're in animals. That's the impression that we have. That perception we need to kind of fix, but that's just my other soapbox. It's the ability that they actually had some information and was that negative impact. Then they still felt that it was important for them to continue or start in the study because they talked to their provider. Their provider mentioned that as a possible option. Then once they got through the consent they learned a little bit more about it and decided regardless we want to continue because it might help us.

Then the last one is how do you think us as professionals—we can reach out to the communities better? It really kind of boils down to word of mouth from a patient who has had, in their case, a positive experience about the study. That is kind of what the take home message is for that. Dr. Elliott?

**Dr. Elliott:** I would say to piggyback onto that from the patients' perspective as a provider the most important thing is they understand that you're a partner in their health. You are not there to treat them as a study subject. You're not there to generate revenue. You're there to make them better. When they realize that they don't have the resources or when they realize they don't have the other options whether or not it's the kind of coverage that they may or may not have—when they recognize that you've extended yourself to offer them an opportunity to participate in something that might make them better, then it becomes a much stronger relationship where they then turn around and they do talk to their friends and family and they do recognize that research is not something where you're a study subject but you're a participant and you're a partner in that process.

**Dr. Sandoval:** One of the things that mentioned to me earlier was that one of the reasons that she is able to stay in the study and likes it is because we offer her
transportation. We send a car and bring her to the clinic and send her home or wherever she needs to go.

**MS. MARACHELIAN:** Yeah, and then just adding to the approach. The one size fits all does not work for the Latino community. We have such diversity of countries of origin, and that needs to be addressed, especially in the larger United States to really discuss that and have representation. That's really important. Questions?

**DR. RIOS:** One thing that hasn't been addressed is from the perspective of a community health center how do you engage junior faculty. You're senior faculty with the business doing clinical trials for pharmaceutical companies, but what about the junior faculty that are under Ruth Zambrana's leadership in Maryland or Johns Hopkins? We've got different universities, so how do you engage them? How do you recruit them as a clinic or as researchers, as patients? How do we find those providers out there that we need to engage for more Latino research?

**DR. SANDOVAL:** I would say, you know, at Mary's Center—for those that are not aware, we have approximately a little over 40,000 patients. We have, like Alis said, five sites, soon to be five sites. We have an awful lot of research opportunities that come into this facility. Typically, at an FQHC the turnover rate for a provider because they're paying off student loans they might not stay there that long. The average loan duration repayment is three years. You're trying to worry about attrition. You're worried about providers staying for a long time. As a consequence of us being the type of organization that we are, we get approached by other researchers. Therefore, we allow those junior—I don't want to call them junior physicians but the younger physicians. We get them involved in terms of being like a sub-investigator. We get them involved to understand how it's integrated into the system, so they themselves eventually matriculate to becoming a principal investigator. That is probably the hardest challenge is when we are working with sponsors to say we have the patient population. Then we have new junior investigators are coming along or a provider who has zero clinical research experience but he sees or she sees the exact patients that we're trying to take care of in the study. My biggest soapbox when I speak at conferences is I say to them you need to allow these individuals to participate in clinical trials to be investigators because unless you open the door the current physicians that are conducting clinical trials unfortunately are dying out. The new guard is not having the experience.

Mary's Center does a beautiful job by having—so Dr. Elliott is one of our investigators. Dr. Sandoval is also an investigator on another study we're doing as well. It's grabbing these junior faculty and making them sub-investigators so that they get that experience so that allows them to continue to grow in their careers as physicians and as scientists, which is so important.

**MS. MARACHELIAN:** One of our requirements for actually the research review is that somebody from Mary's Center be a co-PI or a research collaborator. We will not accept anybody just coming in for not just the clinical trials but like the social services, the health education ones, the mental health ones. Somebody from Mary's Center is required to be a co-PI.

**DR. PAGAN:** That's a great point. I'd just like to echo that one of the concepts that I have been promoting is community based participatory funding. We've always done that in our work is whenever we get these large grants with the exception -- we always have a subcontract for the community health center staff to be involved. It does a couple of
things. Experienced individuals who know the community, but in terms of intervention work that I do, the curriculum, the experience stays with the organization and the staff that are under that.

I came up because I wanted to comment on the idea of getting researchers involved in community based work at the health centers. There are two strategies that we’ve worked out at our health center. One of them is because physicians do move on not everybody can work at a community health center for very long. Some do. When you do have those rare birds that are there and you sense that they're getting burnt out, one of the strategies we've used to spice things up is to get them involved in research, put them on the contract, put them on the grant, and buy out a portion of their time with the NIH funding. I think that's a good strategy.

The other strategy is to bring an ivory tower researcher from the university down to work part time and maybe in their particular specialty like geriatrics or cardiology. The clinic will then sub-pay the university to cover their salary to keep it whole with fringe benefits and everything. Those are the two strategies that I think are really helpful to get committed people into the community clinics.

**Discussion**

Cultural competence goes beyond culture. What we really need is diversity competence because every single encounter that we have with patients—that is a cross-cultural encounter of at least seven or eight different cultures. I have experienced with the people that I mentor is that they don't reflect on where they are coming from. There might be the culture of the institution, the culture of the professional specialty, being from an urban background, a rural background. That element of reflexivity is an extremely important one, and it goes beyond culture.

I think we need to have patient spots and community leaders engage early in the research question. Could you share a lesson learned when ARC story where you heard from the community, the community leaders, the patients having a different priority in the research question and how you dealt with it? I think that's a huge challenge, and people can overcome it but it takes time. I would love to hear your stories.

**DR. GIACHELLO:** Well, very briefly. I can talk forever. A couple of things. I deal with it in several different ways. First, I do a community consultation before I determine what should be the research agenda, the issues to be discussed. Once there is an announcement from the federal government or whatever foundation, immediately we call a community meeting of diverse individuals that represent different sectors of the Chicago area. Then, I tell them openly there's this announcement, an opportunity to be able to benefit our community, but I need to hear from all of you what are the issues related to the scope of this application. Some of you are interested in getting involved or you think that we should focus.

It goes to a process of evolution. First, you have a larger group that are trying to come to the meeting and push their agenda, you know, for the right reason. Then, from there once the scope is narrow then you continue meeting with a smaller group that then get actively involved in the actual development of the application, getting all the letters of support if that's needed, developing the letters of agreement when we need to provide that to the funder and refining the final effort.

Very clearly, because money is so critical—very clearly in the very beginning you want to negotiate... You know, you want to tell them this is—if they, in fact, allow, this is what we have available. Unfortunately, university keep whatever percentage. We need to know based on these expertise or knowledge of areas that you're going to be helping us with what kind of contract agreement with financial support can we be able to develop with
you. Then we list all the different activities whether it's focus group, interviewing, telephone interview, face to face, whatever. From there, you develop a contract agreement where there's transparency. Everybody knows what is being negotiated with the other person because, you see, when you call a meeting the directors of those organizations are sending the person to say find out how much money is available if we could get something out of it. I mean that’s the reality.

We wanted to make sure that it's transparent, that there's trust that they know where we are. At the same time, I remember working with - - in a genetics study where the—what is it. HRSA and March of Dimes were the funders. We tried to follow some of the community meeting activity, but HRSA and the March of Dimes told the people we have $250,000 and who wants it? You don't do that because you have to first of all make sure that you follow the directives of the application, the kinds of issues that you need to figure out who is going to get money and if they're going to get a large contract. You need to make sure that the agency has the structure in place and many other elements. Then you need to identify the community leaders and engage them, develop trust with them, and then gradually let them know that there's money and that we're going to be fair in the distribution of the resources.

Sinsi Hernandez:
I actually have participated in developing guidelines at the American Academy of Pediatrics as a parent, right? It's always very challenging to see how researchers are talking about all these measures and outcomes and numbers and not really having that much of an opportunity to talk about what matters to patients. Like how do you measure did my kid actually sleep last night, right? Or did my kid—was my kid able to go to school? That often is not included in what researchers are looking at. That is what patient centered is all about.

At the same time, I am now functioning on the PCORI addressing disparities advisory committee. One of the frustrations that we also see is that—and we talked about it today—is that a lot of the questions that we want answered—they're not set up to be able to answer. As much as we want to like challenge them and say you got it wrong, we really have to understand that their charter ends in 2019. We don't know what's going to happen after that, and so we need to figure out how the community we -- right?

One of the main issues is that they need very specific questions that compare interventions. Too many times when I ask why aren't more studies on Latinos, the answer is 'because we're not receiving proposals that are comparative research'. It's really important that we -- have very specific questions of comparing one thing to another. Then the other thing is that the issue of how to address social determinants is really important for improved health in our communities. How do we work with researchers about Hispanic patient engagement to link to promotoras who are important to educating our community?

DR. RIOS: I'm just going to make one comment and tell you what I said at the beginning. This is about our research agenda, Latino population research agenda from those who do research, whether you're Latino or not or whether you're a researcher. I was asked to make the comment that we are talking about young researchers, young career faculty. How can they be recruited? How can they be mentored? We're also interested in understanding how to recruit the medical students, the public health students, the social work students to be part of a research team. We want to know from all of you, how best to work with our patients in research studies. The social determinants of health are key. How do we push that agenda by saying that's what's missing to do more effective patient outcomes research in our community is to have more supported documented publications.

I wanted to also say that we're looking at the whole continuum of healthcare. It is
how do you get patients to come into the healthcare system, but before they get into the healthcare system—and I would say that prevention programs and community based programs is where the most important information is and also in the media—how do we get people to know that there are health interventions available? How do you stay healthy? You don't have to go into the doctor's office except to have your checkups, right? Then you have these acute care episodes. It could be in an urgent care center. It could be in a clinic. It could be in a doctor's office or a mental health clinic. Acute episode where you need some type of antibiotic for your infection or high blood pressure medication for your high blood pressure. Some people, you know, in our communities go to emergency rooms for care. Then there's the chronic care. In chronic care you look at people that have chronic diseases. Most of us in our 30s, 40s are going to start developing some chronic illness whether it's asthma, hypertension, hypercholesterolema, diabetes. You have to have chronic care, which is different than a one-time acute care episode. Chronic care could be going to doctors that are primary care, and their referrals to specialists. Then you go to lab tests. Then you go get x-rays. After so many years of chronic disease, you end up having to be hospitalized whether you're a diabetic or you're a heart patient or a cancer patient. The hospitalization then is a different setting with a different type of care, which could be researched.

I was on a committee for the Robert Wood Johnson that compared cultural competence interventions and the costs of care at ten different healthcare systems in the country. At one hospital in Philadelphia, Hispanic bilingual nurses were utilized in one wing in a hospital to show effective care to a predominant Hispanic population and the decrease in costs. The hospital had the vision to support a systemic change and that is what we need to consider – how to be creative regarding Hispanic patient engagement.

After hospital care you get discharged. Now with the care coordination that is prevalent, the importance of patient-centered medical homes where doctors that are out in the community have a care coordinator that works with them to interact with the hospital. It used to be discharge planners, a social worker at the hospital. Now it's a care coordinator who actually works between the hospitals and different doctors' offices so that they know where their patient went. Now we have doctors that are hospitalists inside hospitals.

These discharge and care coordinators are now probably most important to keeping track of patients. It's the nurses. I don't know who is involved in research with your community health centers - - the nurses. The nurse care coordinators of the future. They're going to help the patients that are hospitalized to make sure they have health related—I'll just say the transportation, the care giving, the meals on wheels—all the community resources needed for people that have to have continuous care, home care or rehab care in a nursing unit of the hospital where they're just there temporarily. So the care continuum continues to long term care and care giving. Are your patients going to be living in a home, in an assisted living, in a nursing home or at home? Who is going to be giving the care? Then after long-term care, at the very end of life, it's hospice care. If it's not called hospice care, it's at least talking to the patients and the family about advanced care directives. That's a whole continuum.

And each step of the way, there are social determinants of health that impact the care to Hispanic patients. Choose your point along the continuum and discuss all the realities that our patients face and our families need. That's the kind of research we need to create.

This day is not meant just for PCORI. This discussion is needed so that we can as a National Hispanic Health Foundation start building a place to go to for principles of research. We plan to continue to work with you and others on disseminating this knowledge in a report and also continue to facilitate more research training activities about
Hispanic patient engagement. Let's give a hand to all of our presenters this morning.

**Recommendations to Advance PCOR Research for Hispanic Health Research**

**A. Hispanic Patient Engaged Research Agenda Priorities**

1. **Focus on a lifespan approach**
   - Priority issues are with aging and geriatrics prevention and management
   - Research along the lifespan with Hispanic focus
   - Also look at the dynamics of intergenerational care giving, differences in healthcare seeking

2. **Healthcare delivery approach**
   - Patient outcomes in ACOs
   - Limited physician networks and referrals
   - Incentives – ROI & inform impact on community for value based care
   - Measures for health equity
   - Technical assistance from CMS on Latino subgroup data

How can hospitals/health care centers use community needs health assessments help PCOR? Hospitals not involving community to a certain extent → how do you change flow of funds given? & how do you persuade hospitals to use their funds
What economic incentives will encourage health care facilities to engage in PCOR w/ Hispanics?

3. **Big Data Needed**
   - Forecasting specialty needs
   - “New is better” – bad mantra
   - Science meets service
   - Holistically address community, gender, SES, subgroup
   - Evaluate health services by SES and race/ethnicity across generations

4. **Language Services**
   - Include appropriate translators and interpreters for more effective interpretation on the research team
   - Recruit from your local Hispanic population for services
   - PCORI to allow budget for appropriate language translators

5. **Cultural Competency**
   - Cultural adaption, flexibility of research design of academic leaders should be considered in the clinical effective research protocols
   - Patient Engagement requires training about Hispanic subpopulations and cultural competence
   - Community Education is key
     - Develop relationships with community partners for research studies
     - Inform community so that patients learn about research studies
     - Dispel mistrust of researchers
     - Need to use bilingual staff

6. **Patient-Centered Research Protocols**
   - Longer project period is needed for research that is patient centered → (3-5 years)
   - Include patient-centered partnership and trust development, recruitment, training on developing this
Support development of informed practices - inclusion/expansion of “values,” traditional health/culture, resources and time needed for planning and implementation of working with providers
If you decide to work with a community health center, consider 3-5 years to build a collaborative approach with patient-centered research
Work with Clinical and Translational Science Awards of NIH –
(The CTSA Program is designed to develop innovative solutions that will improve the efficiency, quality and impact of the process for turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public.)
Teams and interdisciplinary training is important to increase patient and caregivers/family research
Improve methods in health system data collection to support PCOR w/ Hispanics

7. **Research topics:**
   - Lifespan/questions
   - Comorbidities
   - Diabetes
   - Asthma
   - Emerging diseases – Zika, Ebola, Dengue, plague (global emerging diseases hit Hispanics)
   - Violence (genes)
   - Adverse child events
   - Payment methods/systemic issues for poor, middle class
   - Family care-giving

8. **PCORI Grants Process Improvement**
   - Review process needs higher Hispanic focus (not just inclusion)
   - Responsive practice in review process
   - Latino needs/incentives to increase responsiveness
   - Indirect costs should be included to the grantee if work is done off campus
   - Subgroup focus should be a priority

9. **Workforce development**
   - Promotoras- educators, researchers, bridges
   - Medicare and Non-Medicare populations are key to studies about healthcare studies

10. **Strength-based approach**
    - Patients
    - Clinical vs social studies (& type of patient) different approach
    - Diversified team
    - Trusted company
    - Study parameter & type of research
    - Barriers (ie. Language, translation, religion, etc)
    - Advertisement (ie. Word of mouth)
    - 1-1 interaction
    - Providers
    - Mentoring/coaching
    - Funding
    - Transition support
    - Caregivers/other
    - Advocates
    - Family across all
B. Priority Research Strategies for PCOR and Hispanic Patients

1. **Connecting Message & packaging (Humility-culture-investigator accountability)**
   Motivation – the Why?
   Buy in /trust
   Results sharing w/ patients/participants - ask them how they would like to receive the results/findings: in person/individual – group forum – phone-email

2. **Enabling Factors**
   Location
   child care, refreshments, time, transportation

3. **Communications**
   Maintain communication and feedback to organizers
   Retention / Attrition are key focus areas
   Identify the point of contact in the community to communicate with the patients
   Meet participants in community

4. **Partnership Building**
   Multiple partners that understand community
   ID community stakeholders that are in alignment with research and topics
   Commit to work together
   Form Community Advisory board - patients/clergy/community leaders, Business/owner, Educators, other key community leaders
   Build-in meetings to listen to research plans, results and provide testimony and feedback
   Plan a celebration at the end of a study

5. **Sensitize Providers to the Importance of the Research**
   Knowledge to help build understanding and buy in
   Continue building TRUST/ continuous communications
   Peer is important. Someone who already participate in the research
   Social media can also be a helpful tool

6. **ID priorities – Data and New data**
   Experimental - ID research topic
   Seek funding for pilot
   Review all processes
   Incentives/training/hiring
   Review of process
   Findings/reporting
   Disseminate to community
   Replication to larger target area
   Capacity building
   Training
   Human subject certified (CITI)
"To promote the public's trust in the research enterprise by providing high quality, peer reviewed, web based, research education materials to enhance the integrity and professionalism of investigators and staff conducting research." **CITI Program Mission Statement**

Help new groups / other groups  
Presentations and Publications  
Diversity in studies – include undocumented  
Community engagement - redefine infrastructure for TRUST and sustainable support beyond a single clinical trial  
Invest in the community/promotores - stable employment, living wages  
Policy – wise reimbursable expenses  
Buy-in academic institutions and the community  
Setting clear population recruitment goals + being transparent about how far you are  
Link focus to clinical trial diversity  
Leverage patient/participant voices & community doctors & health centers  
Clinical trials also in the e clinical works/ EHR and Patient Portal

7. **Incentives**  
That are relevant to community, for example grocery store gift cards  
Include incentive $ in the budget  
Refreshments (not a meal)  
Child care, transportation  
Provide more of the community opportunities to participate

8. **Research Effectiveness**  
Citizen model/navigator  
Design with standardized training/scripts  
Humility  
Changing expectations  
Getting to know the person  
Showing care  
Engage/share stories  
Avoid jargon/acronyms  
Patience/listening  
Recognize that researchers can learn from the community  
Explain how it will benefit the community  
Disseminating findings as we collect data  
Recognizing that they are working people  
Recognize that SSN is the top missing piece of info  
Consider income and recognize that income supports multiple family members  
Immigration issues (documentation), don’t ask legal status questions  
Expand it to all Hispanic/Latino subgroups  
Transient community  
Collect individual data  
Recognizing some studies are too long or too difficult to stay in
Intersectionality
Look at people who are predisposed to a disease, not just those who already have it
Focus on the true determinants of health and involve the community

C. Research Training Strategies

1. Interdisciplinary Training Strategies
Cross disciplinary collaboration/cross pollination learning & communication
Understanding what community engaged research along with respect for the community. Set standards & curriculum.
Bed side manner for researchers.
Ethical Issues
Issue focused/disease stakeholders
Knowledge about the community in question- social, historical, values based
Comparative work to include SES and social determinants of health factors
Knowledge of community based resources & mapping including leadership
Leadership development for individuals & community needs.

2. Core Competencies for Training PhDs
Curriculum training
Participatory research/ common engagement
Collaborative approaches for PCOR
Grant writing (NIH, CDC, PCORI, foundations, F, K, R’S)
Research methods
Publishing
Professional socialization/dev
Cultural humility/competency
Social determinants- structural
Guideline based care/EBI/EBC (decision making)
Health systems/navigation
Learning collaborative
Research ethics- human subject
Leveraging
Fellowship opportunities

3. Training Physicians
Recognize that there is small wiggle room for additional curriculum component in CME:
   Limited in patient involvement- patient mentor
   Lack research careers discussion
   Preventative medicine link opportunity

Lack of mentors
Forgetting information learned in first two years
Include more public health/epidemiology classes
Encourage research in hospital in service training regarding patient control
Lack of funding
Losing efforts after residency
Differentiate what communities would benefit
Networking opportunities and support system
Limited funds - apply for grants
Multidisciplinary research environment
Invest time in a specific topic of interest
Be a player in PCOR
Provide scribes for more one on one patient interaction
Track program (focus)

4. Training Undergraduates, Medical Students
Expectation-
Students will gain basic understanding of clinical, basic, translational research
Infrastructure for faculty mentoring - incentivize faculty mentor, faculty development

Research needs to be a component of medical education and embedded in curriculum
Re-timing existing medical schools with electives in advanced research

Curriculum components:
History of research - ethics, Belmont report/ CFR
Progress in development - phase I, II, II, IV/ public health-social
Understanding statistics
Protocol Design
Study approval process
Study expectation - data collection/ analysis
Study constantly in residency

Students need to be evaluated

5. Training Administrators: signing officials, CFO, CEO’S, COO’S, Grant managers, academic higher levels (deans)
Understand the actual research - especially side effects and objectives (go beyond organizational politics)
Understand how funding agencies/mechanism works – ROI with corporation, foundation research programs
Keep clear finances - outstanding balances could jeopardize research
For government research money - understand that admins are custodians of taxpayer money
Sensitive of the type of researchers - mental health
Receive results in simple terms/ science for nonscientists, brown bag lunch lecture
Team player - piece of puzzle perspective
Reciprocal understanding of roles
D. Mentoring Recommendations

1. Mentoring Physicians
Latino/a mentors are overwhelmed
There is a need to reward them
Dual funding
   - Mentee
   - Mentor
Create “mock tenure, promotion, grants etc.” committee/s that can help faculty figure out the system.
Create mentoring environments that include a diverse interdisciplinary group
Make sure mentors are culturally competent (Need for cultural humility and learning how to have it)
Career path mentoring and life/work balance
Creating programs to develop Latino focused mentors
Learn how to say No

2. Mentoring Strategies
Mentor can teach mentee professional writing skills in collaboration with health specific CBO
Use those data for publications with help of mentor
Mandate NIH to provide fellowship funding for graduate and postgraduate mentors
Training grants
Group mentors via institutes such as PRIDE IQRMI graduates for institutes for evaluations/CBO’s

3. Mentoring Faculty
Topic: curriculum/guidelines for faculty mentoring
Possibly all faculty do not have the qualities to mentor
Self-identify and the institution must invest in training
Diversity in mentoring programs
Institution must invest in the mentoring process
Guidelines for mentee
Should be taught what they should expect from mentor
Learn how to select how to select a good mentor.
Guidelines for both mentor and mentee
The relationship should be mutually beneficial
Develop a formal working relationship
   - Example: how often will thy meet?
   - What will authorship on manuscripts be?

4. Mentoring Strategies For Both Mentor and Mentee
Politics of context
Environment
Academic
Doctor’s office
Clinic - How to navigate
The “culture of you professional world when you are alone?
How to deal with inconsistencies?

5. Mentoring Strategies for Mentees
Humility
Awareness for guidance in new failure; “Learning opportunity”
Professional and personal issues
Intentions/goals
Balance (quality of life)
Resources: The goals from the book “Habits of Highly Effective People”
Books “Talent is Overrated” and “Learning How to Move On”

6. Mentoring Strategies for Mentors
“Safe Space”
Gripe sessions (Whine and dine)
NIH NRMN (National Research Mentoring Network)– link to this coalition for increasing diversity in research mentoring
Cultural matching
Platforms of learning
Casey Network, RWJF
Policy is important
Follows trainee successes
Types of mentors: Primary – institutional, Career mentor, Cultural mentor
Goals: Short term, Long term, Career
Check in weekly
Research mentoring
1. Nurture autonomy
2. “See one, Do one, Teach one”
3. Safety net for fragile ego
   - Mentoring / mentee demonstrations
   - Key questions
   - Understand nuances of culture
   - Scientist mentor
   - Brown bag sessions
   - We have to help & understand each other
      o Shared vulnerability
   - Team effort; breaking down barriers/hierarchy
   - Learn from other administrators (peer to peer) / sharing institutional history
   - Partnership vs hierarchy
   - Lack of H/L administrators
      o Less knowledge about the career
   - Groomed/developed bared on talents
      o Clear career vision/role model
CONCLUSION

The National Hispanic Health Foundation (NHHF) convened key Hispanic academic researchers in two meetings in Washington, DC from medicine, public health, dentistry, economics, and social work along with national policy-analysts and advocates to discuss how to expand patient-centered outcomes research (PCOR) about research with Hispanic patient engagement. We hope this report provokes the planning and coordination of more effective ways to include Hispanic patients, researchers and community leaders in innovative research, and research training and mentoring that can improve the health of our Hispanic communities and all Americans.

About the National Hispanic Health Foundation

The National Hispanic Health Foundation (NHHF) is a 501c3 nonprofit foundation established by the National Hispanic Medical Association (NHMA) in 2005. The NHHF mission is to improve the health of Hispanics and other underserved through research, education and charitable activities and is guided by a distinguished board of nationally recognized leaders in healthcare.

NHHF is located at the New York Academy of Medicine and is affiliated with the Robert F. Wagner Graduate School of Public Service, New York University. The major programs of the Foundation were started with support from the Office of Minority Health, U.S. Department of Health and Human Services, including activities focused on Education, Research Training, and Information Dissemination.

Finally, with the New York Academy of Medicine and our partners such as PCORI, NHHF will continue to develop Hispanic patient-outcomes health research, training and publications working in multiple sites and with various healthcare professionals. See www.NHMAFOUNDATION.org for more information.
Appendix I.A. National Hispanic Medical Association
20th Annual Conference

Renaissance Hotel, Washington, DC
April 24, 2016

National Hispanic Health Foundation

Agenda Setting-Meeting on Patient Centered Outcomes Research
AGENDA

11:00 – 11:15 am Welcome and Introduction
Elena Rios, MD, MSPH, President, NHHF
Mark Diaz, MD, Chairman, NHHF Board of Directors

Purpose: to share Lessons Learned regarding Latino Patient-Centered Research from Principle Investigators of Hispanic Health Patient Focused Research with Multi-Academic Institution and Community Partners and Patients w/ Cancer, Diabetes, Heart Disease, and Mental Health

Moderator: Jose Pagan, PhD
Director, Center for Innovative Health Research, New York Academy of Medicine, and Professor, Mt. Sinai School of Medicine, NY, NY

11:15 am – 11:35 am Keynote Speaker: Overview of Hispanic Health Research and PCORI
Alicia Fernandez, MD, PCORI Board of Directors
Professor, University of California San Francisco School of Medicine

11:35 am – 12:05 pm Panel 1. Hispanic Patient-Centered Research: Lessons Learned Conducting PCOR with Hispanic/Latino Communities.
Hector Balcazar, MS, PhD
Dean, School of Health and Sciences, Charles R. Drew University School of Medicine and Science, Los Angeles, CA

Gregory Talavera, MD
Division Head, Division of Health Promotion and Behavioral Science
San Diego State University

12:05 pm – 12:30 pm Working Lunch

12:30 pm – 1:15 pm Panel 2. Hispanic Health Research Training: Lessons learned in Patient-Centered Research Training for Hispanic Stakeholders including Patients
Aida Giacello, PhD
Professor of Medicine in Preventive Medicine
Northwestern University Feinberg School of Medicine, Chicago, IL

David Hayes Bautista, PhD
Professor, UCLA Fielding School of Public Health
Director, UCLA Center for the Study of Latino Health and Culture

1:15 pm – 2:00 pm  Workgroup Discussion – Strategies for PCOR with Hispanic Patients and Training Young Faculty

2:00 pm – 2:45 pm  Report out of Workgroups

2:45 pm – 3:00 pm  Closing Remarks: Evaluations to be collected.

This meeting is being supported by a contract from the Patient Centered Outcomes Research Institute (PCORI)
APPENDIX IB
National Hispanic Health Foundation

Beacon Hotel, Washington, DC
June 29th, 2016

Meeting on Patient Centered Outcomes Research
AGENDA

8:00 – 8:30 AM  Breakfast

8:30 – 9:00 AM  Welcome and Introductions

Elena Rios, MD, MSPH, President, NHHF
Jose Pagan, PhD Director, Center for Innovative Health Research, New York Academy of Medicine, and Professor, Mt. Sinai School of Medicine, NY, NY

9:00 – 9:15 AM  Overview of the Day

**Purpose:** to develop Latino Patient-Centered Research Agenda from Principle Investigators of Hispanic Health Patient Focused Research with Multi-Academic Institution and Community Partners and to discuss priorities for a National Hispanic Health Research Center.

9:15 – 10:30 AM  Overview of April 24th 2016 Meeting, Hispanic Health Research and PCORI

Aida Giachello, PhD
Professor of Medicine in Preventive Medicine
Northwestern University Feinberg School of Medicine, Chicago, IL

Gregory Talavera, MD
Division Head, Division of Health Promotion and Behavioral Science
San Diego State University

Alis Marachelian, MPH
Senior Director, Health Promotion Department
Mary’s Center’s Patient Research Advocate Speaker

Tollie Elliott, MD
Chief Medical Officer
Mary’s Center’s Patient Research Advocate Speaker

10:30 – 10:40 AM  Break


11:30 – 11:50 AM  Working Groups 1 Reports
11:50 – 12:30 PM  Break for Lunch
12:30 – 1:10 PM  Working Groups Session 2. Research Strategies for PCOR with Hispanic Patients
1:10 – 1:20 PM  Working Groups 2 Reports
1:20 – 2:00 PM  Working Groups Session 3. Training Strategies for Young Faculty conducting PCOR with Hispanic Patients
2:00 – 2:20 PM  Working Groups 3 Reports
2:20 – 2:30 PM  Break
2:30 – 3:10 PM  Working Groups Session 4. Mentoring Strategies for Young Faculty conducting PCOR with Hispanic Patients
3:10 – 3:30 PM  Working Groups 4 Reports
3:30 – 4:00 PM  Collect Evaluations & Closing Remarks

This meeting is being supported by a contract from the Patient Centered Outcomes Research Institute (PCORI)
APPENDIX II.A
National Hispanic Health Foundation
Renaissance Hotel, Washington, DC
April 24, 2016

Agenda Setting-Meeting on Patient Centered Outcomes Research
RSVP List

Camilo Acuna, Medical Student
Latino Medical Student Association
147 W 105 St 1E
646-421-9915
milfuego@gmail.com

Sara Agate, MPH
Congressman Xavier Becerra
1505 12th Street NW
847-971-1572
sara.agate2@gmail.com

Richard Aguilar, Medical Director
Diabetes Nation LLC
7705 Seville Avenue Suite B
562-896-7969
rbiz@raguilar.us

Cristina Alvarado Nieves, Endocrinology,
Diabetes and Metabolism Fellow
University of Massachusetts
469 Boston Turnpike Apt 8
787-307-3573
cristina.alvaradonieves@umassmemorial.org

Diana Andino, Medical Student
Stritch School of Medicine
114 Chicago Ave 1R
832-231-6073
dandino1@luc.edu

Samuel Arce, Chairman, Board of Directors
National Hispanic Medical Association
89-06 133th Street
718-658-3355
samarce@aol.com

Orlando Ardila, Medical Student
Howard College of Medicine
orlando.ardila@gmail.com

Hector Balcazar, Dean
College of Science and Health
Charles R. Drew University of Medicine
1731 East 120th Street
915-274-5016
Hector.G.Balcazar@uth.tmc.edu

Carlos Barrera, Medical Student
Latino Medical Students Association
4171 SW 140th Court
305-223-2449
c.barrera@med.miami.edu

Cecil Mayra Benitez
Stanford University School of Medicine
395 E. Okeefe St Apt. 20
818-653-8380
cecilb@stanford.edu

Russell Bennett, Vice President
Latino Health Solutions
United Healthcare
4 Halsey Avenue
714-306-5975
russellbennett@uhc.com

Cara Buchanan, Medical Student
GW School of Medicine
1401 S St NW Apt 406
702-373-3111
cara.buchanan@gmail.com

Edgar Bustamante, Medical Student
Howard College of Medicine
bust0046@umn.edu

Alejandra Cano, Resident
University of Illinois
808 S Wood St
773-875-5192
acano3@uic.edu
David Carlisle, President & CEO
Charles R. Drew University of Medicine & Biomedical Sciences
1731 E. 120th St
323-563-4987
davidcarlisle@cdrewu.edu

Ruby Castillo-Puentes, Medical Director
Strategic Medical Affairs & Medical Sciences
Johnson & Johnson
530 S. 2nd St. Suite 743
610-864-2528
rcastil4@its.jnj.com

Marisa Castillo, Medical Student
Latino Medical Student Association
210-365-1349
mmc0221@live.unthsc.edu

Maricela Castillo MacKenzie, Physician
DMC Sinai Grace/ Wayne State University
Family Medicine Program
4045 Lincoln Dr
248-821-8372
mcastill@med.wayne.edu

Licia Cerrate-Reinoso, President
Nutricia Dietetic Consults
1400 E Ridge Rd Suite 6
956-534-4814
lcerrate@yahoo.com

Sergio Chiarella, Physician
Northwestern University
3170 N Sheridan Rd Apt 621
312-823-3678
sergio-chiarella@northwestern.edu

Nereida Correa, Associate Clinical Professor
Jacobi Medical Center
Albert Einstein College of Medicine
1500 Pelham ParkWay
914-912-4821
correanereida@aol.com

Ricardo Correa, MD, Es.D, FACP
NIH & Brown University
1 Evie Dr
786-246-5719
riccorrea20@hotmail.com

Mark Diaz, Dr.
Alivio Medical Group
3039 K Street Suite 202
916-448-2998
madiaz@ucdavis.edu

Robert Doherty, Senior Vice President
Governmental Affairs and Public Policy
American College of Physicians
25 Massachusetts Avenue Suite 700
202-261-4530
rdoherty@acponline.org

Jean Drummond, President
HCD International
301-552-8803
jdrummond@hcdi.com

David Elias Virgil
Abrazo Central Campus (Formerly Phoenix Baptist) Family Medicine Residency Program
2000 W. Bethany Home Road
602-246-5525
devirgil@abrazohealth.com

Giovanni Escobedo, Fellow
Congressional Hispanic Caucus Institute
1128 16th St NW.
gyescobedo@gmail.com

Araceli Esquivel, Senior Manager, Vulnerable Populations, Health Care Service Corporation
300 E. Randolph St. Office 5108 - 5th Floor
312-653-7897
EsquivelA@bcbsil.com

Alicia Fernandez, Professor of Clinical Medicine
University of California, San Francisco
1001 Potrero Avenue Bldg 10, Rm 1320B
415-206-5394
Alicia.fernandez@ucsf.edu

Nicole Ferrer, Administrative Director
Intensive Care Experts
17180 Royal Palm Blvd #3
954-225-7694
nferrer@icehealthnet.com

Gustavo Ferrer, President
Intensive Care Experts  
17180 Royal Palm Blvd #3  
754-281-6737  
gferrer@icehealthnet.com  

Judith Flores, Medical Director  
Woodhull Medical & Mental Health Center  
257 Westminster road  
718-809-9752  
judith.flores@nychhc.org  

Alvaro Galvis, Physician  
University of Nevada School of Medicine  
1951 N Jones Blvd  
650-201-4989  
agalvis@unr.edu  

Maria Garcia, Associate Professor of Medicine  
University of Massachusetts Medical School  
55 Lake Avenue North  
508-856-5484  
maria.garciamd@umassmed.edu  

Jorge Gonzalez, Physician  
University of Virginia  
2158 Saranac Ct  
857-294-9646  
jgonzalez@virginia.edu  

Rita Guevara Dohmen, Chief Resident  
St. Christopher's Hospital for Children  
160 E Erie Avenue  
703-307-3321  
guevaradohmen@droxelmed.edu  

Rosibel Hernandez, MD/MPH Candidate 2017  
David Geffen School of Medicine, UCLA/PRIME  
Harvard T.H. Chan School of Public Health  
7948 Chastain Avenue  
818-307-7859  
roh800@mail.harvard.edu  

Miguel Hernandez, MD, ABPN  
Dominican Medical Association  
646-943-1502  

Amanda Hernandez, Medical student  
Latino Medical Student Assocation  

Sinsi Hernandez-Cancio, Health Equity Director  
Families USA  
1201 New York Ave. NW, Suite 1100  
202-628-3030  
s hernandez-cancio@familiesusa.org  

Maritza Irizarry, Medical Director  
Sunshine Pediatrics  
20701 N Scottsdale Rd #107-427  
602-790-0212  
sunpedaz@aol.com  

Sonia Jacome, Research Coordinator  
Northwell Health  
600 Community Drive Suite 300  
516-321-8029  
sjacome1@northwell.edu  

Ramon Jimenez, MD  
American Association of Latino Orthopedic Surgeons  
831-643-9788  
ramon@jimenez.net  

Deanna Kepka, Assistant Professor  
Huntsman Cancer Institute & University of Utah  
2000 Circle of Hope, #4144  
801-587-4565  
deanna.kepka@hci.utah.edu  

Victor Kirk, Chief Executive Officer  
St. Gabriel Health Clinic, Inc.  
5760 Monticello  
318-487-9999  
vkirk@stgabrielchc.org  

Dara Koppelman, Chief Nursing Officer  
Mary's Center  
2333 Ontario Road, NW  
202-545-2063  
dkoppelman@maryscenter.org  

Onelia Lage, Associate Professor  
Florida International University  
11200 SW 8TH ST
Elizabeth Latorre, Corporate Vice President
New York Life Insurance Company
786-537-6452
Elizabeth_Latorre@newyorklife.com

Alfonso Lopez, Consultant
MAXIMUS
1891 Metro Center Drive
443-277-7811
marybailey@maximus.com

Leslie Lopez
Choose Health LA Moms- MCAH LA County DPH
600 S. Commonwealth Ave. Suite 800
213-639-6411
llopez@ph.lacounty.gov

Joseph Lopez, Resident
John Hopkins Hospital
129 W. Montgomery ST
650-353-1599
jlopez37@jhmi.edu

Ana Maria Lopez, Associate Vice President for Health Equity and Inclusion
University of Utah School of Medicine
26 South 2000 East HSEB Suite 5515
801-585-3338
anamaria.lopez@hsc.utah.edu

Gerardo Lopez-Mena, Executive Physician Community Engagement
Doctors Hospital at Renaissance
5501 S. McColl
956-362-7360
g.lopez-mena@dhr-rgv.com

Erica Lubliner, Resident Physician
UCLA/Kern
3204 Pesante Road
949-394-7367
nouvas@ucla.edu

Stephanie Maestre, Medical Student
Howard College of Medicine
Stephanie.maestre@bison.howard.edu

Mankanchan Majhail
Old Dominion University
6901 Stratford Townes way
804-727-9474
mmajh001@odu.edu

Jorys Martinez-Jorge, Physician
Mayo Clinic
200 First Street SW
305-431-0456
martinezjorge.jorys@mayo.edu

Linda May, Physician
UT Health Science Center at San Antonio
3805 East Songbird Lane
832-287-8076
lindase143@gmail.com

Magdalena McCall, Assistant Director
Mexican American Hispanic Physician Association
210-340-8824
magdalena.mccall@UHS-SA.com

Estephany Medina, Medical Student
Howard College of Medicine
Estephany.medina@bison.howard.edu

Ana Melgar, Resident
Community Medicine Fellowship with Kaiser Permanente
1100 E 4 Street Unit 6
626-215-0221

Julio Mendoza, Medical Student
Howard College of Medicine
julio.mendoza@bison.howard.edu

Leonidas Miranda, MD, FACS
Hispanic American Medical Association of Houston
832-713-3541
hamah.info@gmail.com

Pedro Montenegro, Staff
National Hispanic Medical Association
1920 L St Suite 725
626-498-5248
pmontenegro@nhmamd.org
Evangelina Montoya, CAPT. USPHS (Ret.)
Public Health Consultant
National Association of Hispanic Nurses
(NAHN) Washington, DC Chapter
1455 Pennsylvania Ave NW #400
301-527-0989
Emeliaevita@yahoo.com

Natalie Mora, Physician
University of Virginia
2145 Inglewood Drive, Apt 208
914-391-3144
nataliemora@gmail.com

Ruben Mora-Roman, Medical Student
Latino Medical Student Association
37 George St
650-444-1585
rmaroroman@gmail.com

Perfecto Munoz, MA, PhD, MPH
Latino Caucus for Public Health of the
American Public Health Association
310-809-4104
perfecto.munoz@berkeley.edu

Ana Natale-Pereira, Associate Professor of Medicine
Division Director General Internal Medicine
Rutgers-New Jersey Medical School
150 Bergen Street UH-H245
973-972-8994
natalean@njms.rutgers.edu

Carlos O'Bryan, Family Physician
Ventura County Medical Center
2400 South C Street
805-240-7000
carlos.obryan@outlook.com

Molly Orban, Medical Student
University of Central Florida College of Medicine/Nemours Children's Hospital
9017 Savannah Julip Lane
561-801-5501
mawilli@knights.ucf.edu

Rodolfo Orozco, DDS
Alpine Oak Dental
1891 Oak Haven Road
619-249-8987
orozcodental@aol.com

Judy Orozco, Co-owner
Alpine Oak Dental
1891 Oak Haven Road
619-219-4860
alpineoakdental@yahoo.com

Jose Pagan, Director, Center for Health Innovation
The New York Academy of Medicine
1216 Fifth Avenue
956-821-6851
jpagan@nyam.org

Pablo Pantaleoni, CEO
Medtep
1540 Market Street
415-917-6684
pablo@medtep.com

Laura Pantoja, Manager, Quality Management Programs
The University of Texas MD Anderson Cancer Center
7007 Bertner, suite 9.3429
713-563-3057
lpantoj@mdanderson.org

Sonia Parra, Chief Development Officer
Latino Medical Student Association
210-979-1795
sonia.parra@bcm.edu

Hector Perez, Assistant Professor
Montefiore Medical Center
44720 Center Blvd Apt 3012
718-638-0213
heperez@montefiore.org

Elys Perez, Resident
Pennsylvania Hospital
901 Penn Street Apt R1202
786-556-6596

Bert Pineda, Medical Student
Latino Medical Student Association
310-748-9628
elberthpineda@mednet.ucla.edu

Maria Portela-Martinez, Medical Training and Geriatrics Branch Chief
Health Resources & Services Administration
5600 Fishers Lane.
mportela-martinez@hrsa.gov

Jorge Ramallo, Dr.
Howard University Hospital
5893 2nd Street S.
703-881-6584
jir4u@virginia.edu

Vanessa Ramirez, Medical Student
Keck School of Medicine of USC
1814 Pennsylvania Ave
626-622-9605
veramirez0206@gmail.com

Amelie Ramirez, DrPH
Institute for Health Promotion Research - UTHSCSA
7411 John Smith, Suite 1000
210-562-6500
ramirezagoguthscs.edu

Manuel Reinoso, President
Rio Grande Valley Pediatric Gastroenterology
1400 E Ridge Rd Suite 7
956-928-0400
mreinoso@pedgastro.com

Lonnie Resser, Health Educator
Los Angeles County Department of Public Health,Choose Health LA Moms
600 S. Commonwealth Avenue, Suite 800
213-639-6495
resser@ph.lacounty.gov

Nelson Reyneri, Vice President
Liberty Power
1901 West Cypress Creek Road
954-598-7032
nreyneri@libertypower.corp

Sergio Rimola, MD
NHMA
8302-A Old Courthouse Road
703-448-9140
srrdoc@aol.com

Franklyn Rocha-Cabrero, Medical Student
Latino Medical Student Association
787-538-5469
frocha3@illinois.edu

Jessica Rodas, Fellow
Congressional Hispanic Caucus
1128 16th St NW
913-271-9815
jessirodas21@gmail.com

Carlos Jose Rodriguez, Doctor
Wake Forest School of Medicine
Medical Center Boulevard
336-713-1648
cjir10@columbia.edu

Wilfredo De Jesus Rojas, Physician
University of Texas Health Science Center
6431 Fannin St MSB 3.228
787-375-8914
wilfredo.dejesusrojas@uth.tmc.edu

Fernando Romero, Gynecologist
49 Reservation Road
978-474-6426
fmromero@verison.net

Minerva Romero Arenas, Resident
Sinai Hospital of Baltimore
300 Cathedral St Apt 411
602-330-4825
minervies@gmail.com

Valerie Romero-Leggott, Vice Chancellor for Diversity
University of New Mexico
Health Sciences Center
Office for Diversity
1 University of New Mexico
505-272-2728
VRomero@salud.unm.edu

Sylvia Rosas, Associate Professor of Medicine
Harvard Medical School
Joslin Diabetes Center
One Joslin Place
617-309-2477
sylvia.rosas@joslin.harvard.edu

Arielle Rubin, Medical Student
Latino Medical Student Association
aerubin@email.arizona.edu
David Sanchez
Howard
david.sanchez@bison.howard.edu

Jeans Santana, Medical Student
Latino Medical Association
1139 Nelson Avenue Apt. 3D
347-882-8812
jeans.santana@gmail.com

Snehal Shah, Nurse Practitioner
JHCP
1000 East Eager Street
443-257-9956
sshah17@jhmi.edu

Thwe Shein, Infectious Disease Fellow
University of California San Francisco, Fresno
Medical Education Program
381 W Lexington Ave #105
408-207-3482
thwethweshein@gmail.com

Victoria Silverman, Medical Student
Latino Medical Student Association
1200 Brickell Bay Drive Unit 1509
954-594-0739
vms81@med.miami.edu

Robert Smith, MD
Physician Assistants for Latino Health
927-539-6018
rsspac@aol.com

Maria Soto-Greene, Vice Dean and Professor of Medicine; Director, Hispanic Center of Excellence
Rutgers New Jersey Medical School
185 South Orange Avenue, MSB/C-671
973-972-3495
sotogrml@njms.rutgers.edu

Fernando Stein, President-Elect
The American Academy of Pediatrics
141 Northwest Point Blvd.
847-434-7502
dgreco@aap.org

Daniel Suarez
National Association of Hispanic Nurses
501-673-1131
dsuarez@oncourselearning.com

Ruben Taborda, Chief Procurement Officer, Medical Devices and Diagnostics/Supplier Diversity Leader, Johnson & Johnson
rtaborda@its.jnj.com

Gregory Talavera, Professor of Public Health
San Diego State University
450 4th Avenue Suite 400
619-205-1945
gtalavera@mail.sdsu.edu

Roberto Tapia Conyer, MD, MPH, DrSc, MSc, CEO, Carlos Slim Foundation
Trizia.herrera@ppal.com.mx

Ana Tergas, Physician / Clinical Instructor
Columbia University Medical Center
219 W 14 Street Apt 2RW
305-804-7192
ait2111@cumc.columbia.edu

Diana Torres-Burgos, Advisor on Hispanic Health
National Hispanic Health Foundation
1216 Fifth Ave, Rm. 457
212-419-3686
dtorresburgos@nhmafoundation.org

Marlen Trujillo, CEO
Spring Branch Community Health Center
800 W Sam Houston Pkwy S, Suite 200
713-462-6565
mespindola@sbchc.net

Daniel Turner-Lloveras, Physician
National Health Service Corp
10300 Compton Avenue
510-621-3585
mydjtl@gmail.com

Valeria Valbuena, Medical Student
Latino Medical Student Association
903 S Ashland Ave Apt 213
941-840-3035
vvalbu2@uic.edu

Elia Valladares Juarez, Physician
University of Virginia
Kimberly Valle Mejia, Student
NC State
1470 River Run Rd
919-901-5652
kivalm7@gmail.com

Ana Velazquez, Resident
Mount Sinai Beth Israel
353 E 17 St Apt 4A
787-243-5222
amanana@chpnet.org

Aida Vigil, Physician
UT Health Science Center at Houston
6346 Thornwall Street
201-379-0732
aida.l.vigil@uth.tmc.edu

Andrew Villanueva, Medical Student
Howard College of Medicine
andrew.villanueva@bison.howard.edu

Leandra Woolnough, Physician
UT Southwestern Medical Center
5353 Harry Hines Blvd, J4 130J
241-773-7298
leandra.uribe@utsouthwestern.edu

Michael Ybarra, Senior Director of Alliance Development
PhRma
mybarra@phrma.org

Ruth Zambrana, Professor, ADVANCE Fellow
University of Maryland, Department of Women's Studies Director, Consortium on Race, Gender and Ethnicity
3603 Husted Drwy
240-351-0083
rzambran@umd.edu

Claudia Zamora, Strategy Consulting
PricewaterhouseCooper
1800 Tysons Boulevard
202-431-0274
claudia.h.zamora@strategyand.us.pwc.com
APPENDIX II.B
National Hispanic Health Foundation
Meeting on Patient Centered Outcomes Research
Beacon Hotel, Washington, DC
June 29, 2016

Participant List

Philip M. Alberti PhD
AAMC Senior Director for Health Equity Research and Policy
Association of American Medical Colleges/Columbia SPH
655 K Street NW, Suite 100
Washington, DC 20001
202-828-0522
palberti@aamc.org

Larissa Aviles-Santa MD, MPH
Project Director
Hispanic Community Health Study (HCHS)/Study of Latinos (SOL)
6701 Rockledge Dr. Room 10208
Bethesda, MD 20817
301-435-1285
avilessantal@nhlbi.nih.gov

Minerva Campos MD, MPH
Family Practice Physician
Unity Health Care Centers
3020 14th St. NW
Washington, DC 20009
202-612-1114

Olivia D. Carter-Pokras, PhD
Professor of Epidemiology and Interim Associate Dean for Diversity and Inclusion
University of Maryland School of Public Health
2234G SPH Building
College Park, Maryland 20742
301-405-8037
opokras@umd.edu

Ralph DiClemente PhD, MSc
Professor, Behavioral Sciences and Health Education
Emory/Rollins School of Public Health
1518 Clifton Rd
Atlanta, GA 30322
404-727-0237
diclem@emory.edu

Ysabel Duron
CEO, Founder, Latinas Contra Cancer
255 N Market St #175
San Jose, CA 95110
408-280-0811
ceo@latinascontracancer.org

Tollie Elliott MD
Chief Medical Officer, Mary’s Center
2333 Ontario Rd. NW
Washington, DC 20009
202-745-3119
telliot@maryscenter.org

Joseph Frascella, Ph.D.
Senior Science Advisor
Office of the Director
National Institute on Drug Abuse/NIH Neurosciences Center
6001 Executive Boulevard
Bethesda, Maryland 20892
jfrascel@nida.nih.gov

Carl Garrett
Director, Government Relations
Centene Corporation
1150 Connecticut Avenue, NW, Suite 1000
Washington, DC 20036
314-505-6733
cgarrett@centene.com

Miryam C. Gerdine, MPH
Latina Researchers Network, Chair of the Networking and Mentoring Committee and Associate in the Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health
MGerdine@hrsa.gov
Aida Giachello, PhD  
Research Professor, Preventative Medicine  
Northwestern University School of Medicine  
680 N Lake Shore Drive, Suite 1400  
Chicago IL 60611  
312-503-0983  
312-451-4539  
a-giachello@northwestern.edu

Mark Gibbons  
Director of Programs and Operations  
Caregiver Action Network  
1130 Connecticut Ave NW Suite 300  
Washington, DC 20036  
202-454-3969  
m gibbons@caregiveraction.org

Sinsi Hernandez, JD  
Director, Health Equity  
Families USA  
1201 New York Ave NW #1100  
Washington, DC 20005  
202-628-3030  
Sher Hernandez-Cancio@familiesusa.org

Emma Hidalgo  
phybio@gmail.com

Daniel Korin, MD  
Primary Care Pediatrician  
Sunset Park Family Health Center  
150 55th St  
Brooklyn, NY 11220  
(718) 630-7942  
dkorin22@gmail.com

Aurelia Laird, RN, BSN  
Director of Clinical and Community Research  
Bon Secours Baltimore Health System  
2000 W Baltimore St  
Baltimore, MD 21223  
410-362-3254  
Aurelia Laird@bshsi.org

Lara Leticia, LCSW  
President/CEO  
LARA Consulting Group, Inc.  
lc_lara@sbcglobal.net

Alis Marachelian MPH  
Senior Director, Health Promotion Department,  
Co-Chair, Research Review Committee  
Mary’s Center  
2333 Ontario Rd. NW  
Washington, DC 20009  
202-420-7100  
amarachelian@maryscenter.org

Glenn A. Martinez PhD, MPH  
Department Chair and Professor of Spanish  
Ohio State University  
298 Hagerty Hall,  
1775 College Rd.  
Columbus, OH 43210  
614-292-4958  
martinez.474@osu.edu

Pilar Mendez, MPH, BS  
Program Assistant, Research Infrastructure  
Patient-Centered Outcomes Research Institute (PCORI)  
1828 L Street, NW 9th Floor  
Washington, DC 20036  
202-370-9471  
pmendez@pcori.org

Pedro Montenegro  
National Hispanic Health Foundation  
1920 L St., NW, Suite 725  
Washington, DC 20036  
202-628-5895  
pmontenegro@nhmamd.org

Eva Montoya, MSN, RN  
U.S. Public Health Service (Ret.)  
Public Health Nurse Consultant  
NAHN Washington DC Chapter  
1455 Pennsylvania Ave NW # 400 Washington, DC 20004  
202-387-2477  
Emeliaevita@yahoo.com

Ivan Montoya MD, MPH  
Deputy Director  
Division of Pharmacotherapies and Medical Consequences of Drug Abuse  
6601 Executive Blvd. Room 5213  
Bethesda, MD 20892  
301-443-8639  
imontoya@mail.nih.gov
Nagel Richard, MBA, IPA  
Executive Director  
Community Educators to Healthcare Consumers  
www.neighbors-keeper.org  
nagel@neighbors-keeper.org

Leslie Prado, PA, MPH  
Recent Graduate  
George Washington University  
2121 I St NW  
Washington, DC 20052  
860-539-7364  
lprado23@gwmail.gwu.edu

Juan Ramos, PhD  
Retired  
National Institute of Mental Health  
National Institutes of Health

Jason Resendez  
Executive Director  
Latinos Against Alzheimer’s Coalition  
2 Wisconsin Circle, Suite 700  
Chevy Chase, MD 20815  
202-280-0884  
jresendez@usagainstalzheimers.org

Sergio Rimola, MD  
DC Regional Co-Chair  
National Hispanic Medical Association  
srrdoc@aol.com

Elena V. Rios, MD, MSPH  
President & CEO, National Hispanic Medical Association and of National Hispanic Health Foundation  
1920 L St., NW, Suite 725  
Washington, DC 20036  
202-628-5895  
erios@nhmafoundation.org

Andrew Robles-Sol, MA  
National Hispanic Health Foundation  
1920 L St., NW, Suite 725  
Washington, DC 20036  
202-628-5895  
arobles@nhmamd.org

Kenneth Romero  
Executive Director  
National Hispanic Caucus of State Legislators

444 North Capitol St NW # 404  
Washington, DC 20001  
202-434-8070

Adelaide Rosario  
301-594-8683

Emmett Ruff  
Families USA  
ERuff@familiesusa.org

Fabian Sandoval MD  
CEO & Medical Director  
Emerson Clinical Research Institute LLC  
Leadership Council Member  
Society for Clinical Research Sites  
202-239-0777  
fabian@ECRInstitute.com

Luisa Soaterna-Castaneda  
Sr. Outreach Specialist  
Zero to Three  
1255 23rd St. NW, Suite 350  
Washington, DC 20047  
202-638-1144  
lsoaterna@zerotothree.org

Gregory A. Talavera MD, MPH  
Professor  
San Diego State University  
9245 Sky Park Court, Suite 100  
San Diego, CA 92123  
619-594-4086  
gtalavera@mail.sdsu.edu

Melissa Valerio PhD, MPH  
Associate Professor of Health Promotion and Behavioral Science  
University of Texas, School of Public Health  
7411 John Smith Dr. Suite 1100  
San Antonio, TX 78229  
210-562-5517  
melissa.a.valerio@uth.tmc.edu

Ruth E. Zambrana PhD  
Director  
University of Maryland; Consortium on Race, Gender and Ethnicity  
2101 Woods Hall  
College Park, MD 20740  
rzambran@umd.edu
Julie Zito, PhD
Pharmaceutical Health Sciences
University of Maryland
220 Arch Street, 12th floor, Room 216
Baltimore, MD 2120
410-706-0524
jzito@rx.umaryland.edu
Appendix III. Readings


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