

# PCORI ADVISORY PANEL ON PATIENT ENGAGEMENT

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*Winter 2020 Meeting*

Day 2

**January 31, 2020**

9:00am-12:00n EDT

# Webinar Housekeeping



- Webinar is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled
- A meeting summary and materials will be made available on PCORI's website following the meeting
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information on future activities

# Welcome

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Kristin Carman  
Director, Public and Patient Engagement

Tom Scheid  
Chair, Advisory Panel on Patient Engagement

Gwen Darien  
Co-chair, Advisory Panel on Patient Engagement

# Agenda – Day Two



- 9 AM – Welcome
- 9:15 AM – PEAP Spotlight – Brendaly Rodriguez
- 9:45 AM – Discussion: Diversity, Equity and Inclusion Principles
- 11:45 AM – Closing Remarks/Adjourn

# Announcements - Important Upcoming Dates



- March 27
  - Application Deadline, PCORI Advisory Panels
- June 4 - 5
  - Next Meeting: Advisory Panel on Patient Engagement
- September 16-17
  - PCORI Annual Meeting, Crystal Gateway Marriott, Arlington, VA
  - PEAP meeting date, TBD

# PEAP Spotlight

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Brendaly Rodríguez  
Manager, Community & Stakeholder  
Engagement, CTSI, University of Miami

# PEAP Spotlight

## Bridging Communities and Institutions

January 31st, 2020

**Brendaly Rodríguez, MA CPH**

**Manager, Community and Stakeholder Engagement (CaSE)  
Univ. of Miami's Clinical and Translational Science Institute (CTSI)**

**Manager, Consortium Core  
Precision Medicine and Health Disparities Collaborative  
Vanderbilt University Medical Center,  
Meharry Medical College, and University of Miami**

# My Journey...





# Interdisciplinary influences...

- Intercultural Communication BA, MA
- Cultural Studies
- Linguistics, Translation, Spanish language teaching
- Communication Scholar Fulbright - Germany
- Lived experiences working in Puerto Rico, US (Phoenix, Atlanta, Miami), and Australia (Melbourne) for both public and private sectors (language/translation businesses, academic centers, NGO, and a government contractor).



# Clinical and Translational Science Institute (CTSI) - Community and Stakeholder Engagement

**Background:** by NIH award granted to UM to drive scientific discovery and its translation into evidence-based clinical and community practices that improve the health of South Florida's diverse population.

**Aim:** Foster long-term participatory academic-community collaborations & assist UM investigators, students & community partners in conducting community-based and culturally competent research.

**Activities:** Collaborate with diverse stakeholders across disciplines

- FL CHW Coalition
- FQHCs
- Area Health Education Centers
- Health planning councils
- NGOs
- FL DOH



# Strengthen Community Partnerships at Work

## Support to Community Organizations

- At local/regional and state level engagement:
  - **Connect Familias:** provided connections to CDC to be 1 of 3 national evaluation site on diabetes education program (NDEP) on Promotores/community health workers toolkit
  - **Health Choice Network-FL:** research collaborations (U54, RO1, GE, FL-DOH), training Community Health Workers (CHW) for research/community partnerships
  - **Health Council of South Florida (HCSF):** bidirectional partnerships on lectures, conferences, reviewer of K12 applications
  - **Miami-Dade Health Action Network (MD-HAN):** 2 forums on recruitment of minorities into clinical trials/research, co-lead CHW Workgroup and training annual regional symposia (10 yrs)
  - **Area Health Education Center:** DOH CRC screening and provider of smoking cessation sites
  - **FL Community Health Workers Coalition:** co-leadership role, provided panel presentations, state and national advocacy support, state credential development lead
  - **FL Health Equity Research Institute (HERI):** reviewed applications, provided program planning, training and presentations
  - **San Juan Bosco Clinic:** provided CHW core competency trainings and is a participant recruitment site for a K12 investigator

## Health:

Health promotion and healthcare are a team effort!  
Each member of the team with a special role:

- Doctors
- Physician Assistants
- Nurses
- Pharmacists
- Dentists
- Technologists and technicians
- Therapists and rehabilitation specialists
- Emotional, social and spiritual support providers
- Administrative and support staff
- **Connectors: Community health workers and patient navigators**

Equality sounds fair.

Equity IS fair.

CHWs make health equity happen!



# CHWs: Partners/Stakeholders in PCOR

CHWs can assist in PCOR **very unique ways** as patients themselves, patient advocates, and navigators:

- In planning: Inform the questions to ask, the ways to gather that information/data
- In implementation: Identify people that might be interested
- Inform those interested about benefits and risks of participating in the research study
- Recruit subjects/participants
- Collect and inform how to interpret data
- Facilitate bi-directional communication throughout
- In dissemination: Help teams tell the study story via alternate channels and to other relevant audiences in a way they might understand

# First PCORI Contact: PCORI Latina Roundtable



- Invited to PCORI meeting in DC on April 18th, 2013
- 26 Latina healthcare professionals and patient advocates from a diverse group of organizations and from across USA
- Meeting Objectives
  1. Create community and promote interest in patient-centered research among Latina patients and health professionals;
  2. Identify healthcare issues and outcomes important to Latinas for future research;
  3. Identify barriers and gaps in knowledge or opportunities for dissemination and implementation;
  4. Gain input from Latinas on PCORI's research programs; and
  5. Identify how PCORI should engage Latinas in research process.

<https://www.pcori.org/events/2013/latina-roundtable>

<https://www.pcori.org/blog/conversations-latinohispanic-community>

# Meeting Results/Outcomes

- Proposed that PCORI fund research on *promotoras* (CHWs).
- Study the role of certified interpreters with non-English-speaking patients.
- Management of care for multiple chronic diseases among subgroups of Spanish speakers.
- > 75% of participants planned to submit a proposal to PCORI

*Interesting to follow up for PCORI 2.0?*



# Next: Ambassador Training

## Certificate of Completion

This is to certify that

**Brendaly Rodriguez**

has successfully completed the course

PCORI Ambassador Program Training

December 14, 2014



Patient-Centered Outcomes Research Institute

# Precision Medicine and Health Disparities Collaborative - Mission & Goals

## Mission

- Combine research expertise, resources, and community engagement to improve health in African Americans and Latinos/Hispanics using precision medicine.

## Goals

- Develop regional partnerships to improve minority health
- Find new ways to use social, cultural, environmental and biological information to improve health
  - *The right medicine for right patient at the right time*
- Meaningfully engage stakeholders throughout center

# PMHDC Consortium Core – Advisory Board

Logic Model Activity: Establish processes to engage stakeholders in health disparities and precision medicine research.

- **Short Term Outcome:** An advisory board (AB) of diverse consortium partners representing a broad range of disciplines and backgrounds.
- **Impact:** Stakeholders whom are *involved and engaged* in PM/HD research, and PM/HD *research that is informed and responsive* to stakeholder input, needs and priorities
- **Metrics:** Membership Diversity, Level of Engagement, Eliciting/Processing Feedback, Turnover
- **Data Source & Collection:** Calls agendas/minutes/attendance, written feedback, uptake/participation in ad hock tasks/other related groups, partnership evaluation tools, annual satisfaction surveys, etc.

# Eugene Washington PCORI Awards: Training/ Dissemination 2015-2019

EAIN #2219 UMIAMI (FL) and EAIN #7239 UMIAMI (National)

- Based our prior work as a statewide and regional partnership on
  - Developing and implementing a CHW certification process
  - Training CHWs for a various disparities research projects (UM and non UM)
- With input from a National Experts CHW Curriculum Advisory Group (includes patients, and community health workers) we will
  - Developed a PCOR research module that can be used toward state certification when applicable
  - Developed and tested a toolkit with a slides set, a Facilitator's Guide and a CHW Student Workbook
  - Trained CHWs in across 4 states in PCOR and in Spanish (563 by Sept 2019)
- A major step forward in bringing additional recognition and credibility to this fast-growing workforce and creating a culturally competent research workforce in FL, CA, TX, TN.

# Content: Training CHWs in PCOR Toolkit

Supported by PCORI EAINs

1. What is research?
  - How it is different than service provision to patients?
  - What is PCOR?
2. Ethics and Protection of Human Research Participants
3. Participation in Clinical Trials, Randomization
4. Data collection: Qualitative and Quantitative Research Methods Basics
5. Informed Consent Process
6. Study Protocol and Data Management
7. Dissemination of Study Results



# PCOR for CHWs Curricula is Available!

<https://www.pcori.org/research-results/2015/statewide-partnership-training-floridas-community-health-workers-patient>

<https://www.pcori.org/research-results/2017/national-partnership-training-community-health-workers-patient-centered>

**Carmen Linarte**, BA, Research Associate, South Florida Center for Reducing Cancer Disparities (SUCCESS), University of Miami Miller School of Medicine, Miami FL.





# In their own words!

Audio (1 min)-

Mercedes Cruz  
Mercedes Cruz,  
Certified CHW Instructor, Dia de la  
Mujer Latina, TX:

“Well good morning I am Mercedes Cruz-Ruiz, I am with the Dia de La Mujer Latina DFW (Dallas Forth Worth) and it was really an honor to participate in this program.

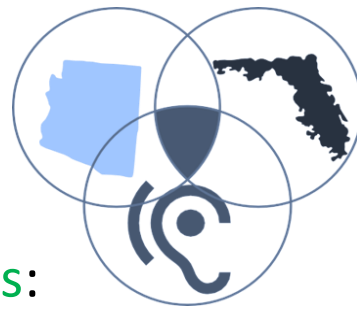
It really brought a lot of knowledge to my area, although I've been participating in research, I needed people to understand what research meant and how they can collaborate and kind of get that taboo about you know guinea pigs in a different light. So it brought a lot of knowledge and it broke a lot of stigma.

So I'm really proud to have been part of the project but even better, to be able to come and present the poster was even greater because it was like every thought and every word that was ever said was put together in a piece of paper and I love that.

Then get the people to explain what we've done and for them to see and say “wow! you guys really did a great job getting out there and getting people involved”. So just so proud to have been here and very thankful to all the people that were involved and especially Brendaly and her efforts because she is from Miami and I am from Miami so it's all good.”



# Hispanic Hearing Health Care Access Coalition



Building **Research Capacity on Hearing Loss Interventions in Hispanic/Latinx Communities:**  
(2019-2021) EAIN UOA #15629

1. Discuss hearing health care disparities in the Latinx community.
2. Discuss breadth of treatment options available and decisional dilemmas that patients face in coping with hearing loss.
3. Describe PCORI Engagement award project planning to inform the research agenda on hearing health care interventions to be maximally supportive of Latinx patients, families and communities.
4. Strengthen existing community partnerships in Arizona and Florida to gain a more diverse perspective from Latinx communities across different socio-cultural backgrounds.
5. Leverage strengths from multiple stakeholders and experts (audiology, public health, translation studies, and community health centers).





# Other Roles at PCORI

- Research Summary Reviewer with PCOR-TC (2017-2019)
- Member, Patient Engagement Advisory Panel (2018-2020)
- Paper and project contributor (Yammer blog, Ambassador Coffee Break series, literature review panelist)
  - <https://www.pcori.org/video/pcori-ambassador-program-august-2018-coffee-break>
- Member, Shared Learning Collaborative: Sustainable Partnerships Group with Trailhead Institute (2017-2019)
- Member, PCORI Research Fundamentals, Training & Resources for Multi-Stakeholder Research Teams, SAG - Stakeholder Advisory Group (2018-2020)
- Member, PDRC LN Representativeness Workgroup (2019-2021)
- Speaking engagements invited by fellow Ambassadors and PEAP panel members

More?

# Get Actively Involved!

- *Get to know more* of the PCOR Community through exploring [www.pcori.org](http://www.pcori.org)
- *Share & Translate Results* through community-based efforts
- *Get Connected* via Coffee Breaks webinars, e-newsletters, social media like LinkedIn/Yammer
- *Get Involved* via merit review, peer review, through research and engagement awards (as EA leads or Research partner)

# Takeaways/Final Thoughts: Q & A time



# Thank you!

- Brendaly Rodríguez, MA, CPH
- Phone: 305-243-8433 | Email: [brodriguez@med.miami.edu](mailto:brodriguez@med.miami.edu)

*Now it's your turn...*

# Closing Remarks

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**ADJOURN**

**(LUNCH AVAILABLE)**

