

# Community-Engaged Research with Latinas in South Carolina: 2000 -2014

Research Collaborations between the South Carolina Hispanic/Latino Health Coalition (SCHLHC) and the University of South Carolina

DeAnne K. Hilfinger Messias, PhD, RN, FAAN  
College of Nursing and Women's and Gender Studies

# 2000: Arrival in South Carolina



# 2000: Other New Faces in South Carolina



Photo: Craig Stinson

# Changing Demographics: Latinos in South Carolina 1990–2010

| Year   | Population | %   |
|--------|------------|-----|
| ➤ 1990 | 30,551     | 1.1 |
| ➤ 2000 | 96,178     | 2.3 |
| ➤ 2010 | 235,682    | 5.1 |

- 1990 – 2000 – 211.2% increase
- County rates ranged from low of 12.4% (Allendale) to 1,624% (Jasper County)
- 2000 – 2011 – 154% increase



# Governor's Ad Hoc Committee on Hispanic Issues (2000)

- Staffed by Commission of Minority Affairs and Office of the Governor (Jim Hodges)
- Five Subcommittees:
  - Health
  - Education
  - Public Safety
  - Human Rights
  - Immigration/Transportation/Fraud

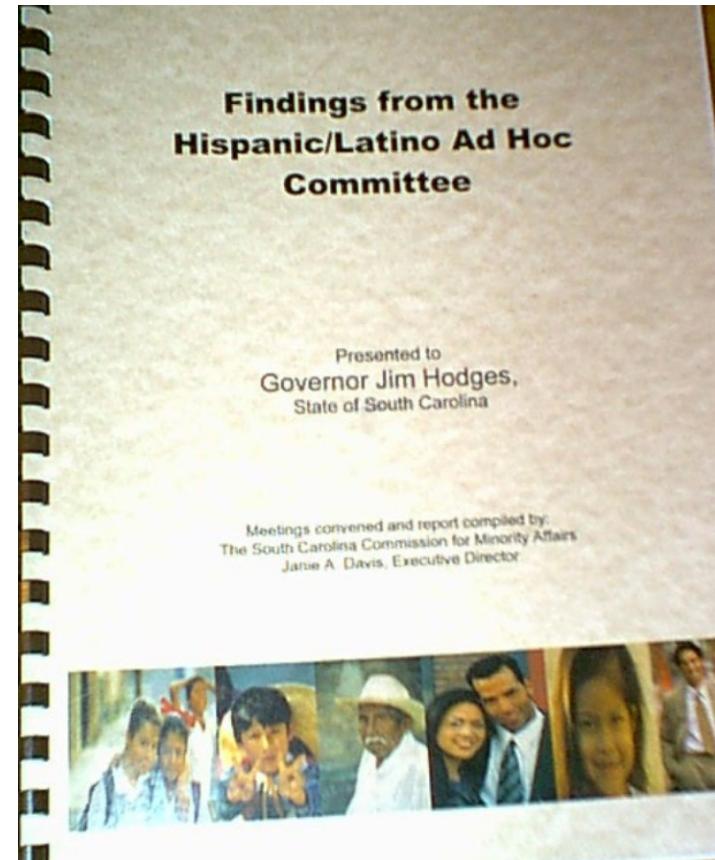
# **Health Subcommittee Process: Engaging the Community**

- ▶ Statewide Representation
- ▶ Diverse relationships/connections with emerging Hispanic communities
- ▶ Participatory Activities
  - Identifying Issues
  - Prioritizing

# Health Subcommittee Findings

## Hispanic Health Issues and Concerns

- Language and communication barriers
- Cultural competency (*mutual competency*)
- Access to care barriers (*cost, insurance, transportation*)
- Lack of data for planning & surveillance
- Immigration and social issues (*documentation; discrimination*)



# Challenges/Underlying Issues

- ▶ Health, Education, and Social Services unprepared for influx of new immigrant populations, particularly those with limited-English-proficiency (LEP)
- ▶ Lack of data to guide policy-making and service provision
- ▶ Lack of established social networks to assist immigrants in accessing services
- ▶ Rising nativism

# *Outcomes of the Health Subcommittee Process*

- ▶ Increased visibility and awareness of this emerging population among providers and policy-makers
- ▶ Inter-professional, inter-sectorial engagement and collaboration
- ▶ Establishment of the South Carolina Hispanic/Latino Health Coalition (granted 501c3 status in 2002)

# SCHLHC Mission

- ▶ To provide coordinated leadership to advocate for equal access to quality health care for Hispanics/Latinos residing in South Carolina.
- ▶ Priorities for action will be in keeping with the guidelines set forth by the National Health Care Standards Culturally and Linguistically Appropriate Services (CLAS).

# SCHLHC Objectives

- ▶ Improve communication among health care service providers, state agencies, and the Hispanic/Latino community.
- ▶ Reduce organizational, systemic, and cultural barriers to health care.
- ▶ Promote “best practices” and cultural competency by agencies and organizations across South Carolina.

# SCHLHC Objectives

- ▶ Foster collaborative efforts and partnerships around specific issues of concern to the Hispanic/Latino population in South Carolina.
- ▶ Serve as a liaison and advisor to public and private agencies and organizations.

# SCHLHC/USC Community Engaged Research Collaborations 2001-2014



# Redes En Acción



The National Hispanic/Latino Cancer Network

## South Carolina Partnership for Cancer Prevention

- ▶ First SCHLHC community-based participatory research partnership (2001–2002)
- ▶ Funded through National Cancer Institute/*Redes En Acción National Hispanic/Latino Cancer Network*



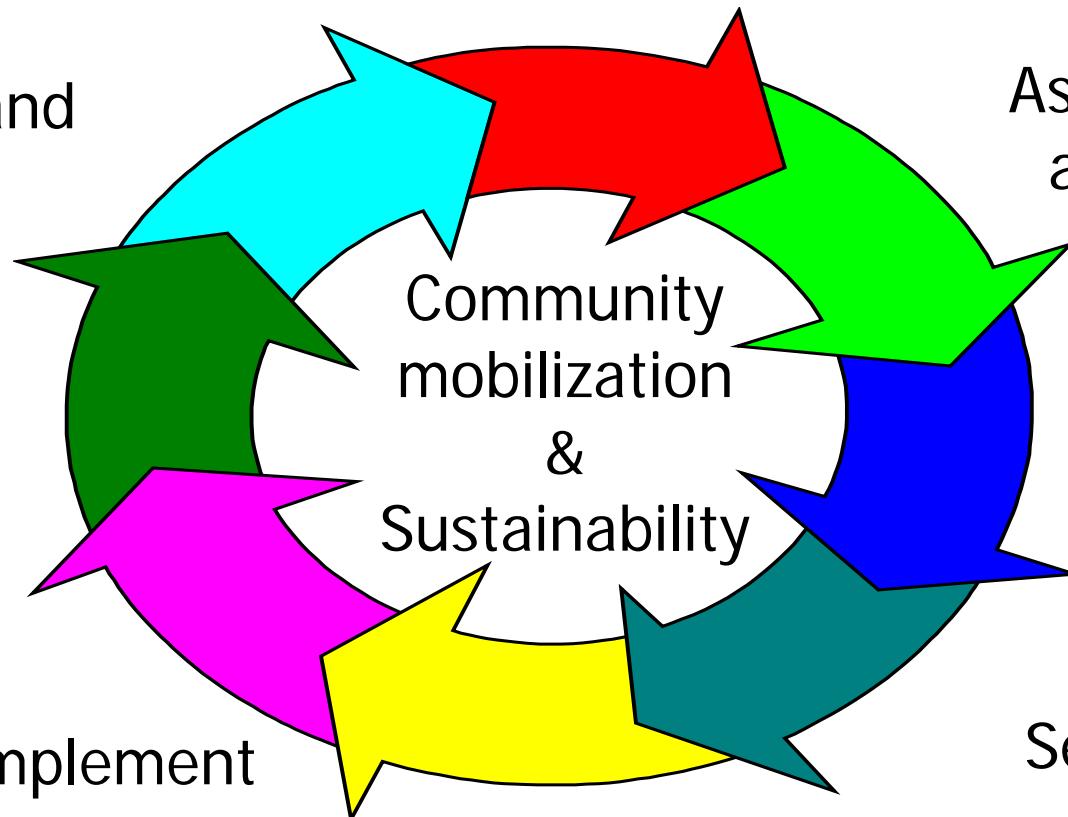
## Community Partnered Research

Evaluate and provide feedback

Assess needs and resources

Plan and implement research

Set Priorities





# ***Redes En Acción***



## **Community Mobilization**

Governor's Ad Hoc Committee  
SC Hispanic/Latino Health Coalition  
Partnership Formation  
Community Outreach  
Collaborative Research

# **Partnership for Cancer Prevention: Specific Aims**

- ▶ Build Hispanic/Latino health partnerships and community capacity in South Carolina
- ▶ Use participatory research to foster the development of the South Carolina Partnership for Cancer Prevention
- ▶ Address Hispanic women's health issues, specifically cervical cancer prevention and detection

# Partnership for Cancer Prevention in Action



- ▶ Getting to know each other – bringing in other partners
- ▶ Brainstorming about access to preventive cancer services in SC
- ▶ Identifying gaps in knowledge
- ▶ Developing a research plan:
  - To assess provider cultural competency
  - To identify Hispanic women's needs

# Partnership for Cancer Prevention Cultural Competency Surveys (N=76)

## Settings:

|                                |     |
|--------------------------------|-----|
| Best Chance Networks Providers | 42% |
| County Health Departments      | 47% |
| Community Health Centers       | 11% |

## Provider type:

|                              |     |
|------------------------------|-----|
| Clinical service providers   | 60% |
| Administrative support staff | 40% |

# Provider Survey Results

- ▶ Majority (55%) reported daily or weekly contact with Hispanic clients
- ▶ Less than 25% were “often” or “always” satisfied with their ability to provide culturally and linguistically appropriate services
- ▶ Main concern was language access (e.g. lack of interpreters and Spanish-language materials) – yet very few (<5%) reported using language assessment tools often or always
- ▶ Discrepancies between *perceived importance* and *actual practice* and relatively low rate of satisfaction among providers in their ability to provide culturally and linguistically appropriate services

# Partnership for Cancer Prevention Community Collaboration: Focus Groups with Hispanic Women



# Focus Group Participant Profile (N = 38 women)

- Average age 33 years (sd = 11 years)
- 73.6% currently married
- 87% born in Mexico
- 61% less than high school education
- 37% currently employed
- 68% family income less than \$1,100/month

# Participants' Cancer Experiences

- Personal history of cervical cancer (n=1)
- 58.6% had pap test < 1 year ago
- 33% had pap test > 1 year ago
- 8% never had pap test
- Most pap tests were in conjunction with prenatal care

# Focus Group Themes

- Lack of cancer knowledge
- Barriers in accessing health care
- US health care system experiences
- Trusted sources of cancer information
- Expectations vs. realities

# Cancer Knowledge

- Common cultural beliefs
  - Blow to the breast is a cause of breast cancer
  - Cervical cancer associated with lack of hygiene or untreated infections
- Limited personalization of risk
- Little knowledge or awareness of cancer etiology, risk factors, preventive measures, or treatment

# Access to Health Care

- Motives for accessing the health care in SC
  - Acute or pregnancy-related care
  - Lack of access for prevention
- The use of informal networks in accessing healthcare
  - Family, friends
  - Informal contacts with providers from formal system
  - Outreach workers and services
  - Preference for group contacts and socialization

# Health Care System Experiences

- US vs. Home Country (Mexico)
  - Degree of familiarity
  - Economics
- Barriers to access to US health care system
  - Language
  - Transportation
  - Insurance/Costs
  - Gender of physician
  - Expectations about provider roles and services
- Health care system experiences
  - Perceived they were receiving “second-rate” treatment



# Expectations and Realities

- Participants perceived physicians to be authorities and trusted sources of information regarding health and illness
- Yet they did not report having sought advice or information from physicians regarding cancer

# Expectations and Realities

- Mothers and women's family social networks are held to be a source of trusted advice and council
- Health, illness, and sexuality issues are not addressed with mothers and other family members

# Implications for Practice: Reaching Providers with Priority Messages

- Providers need to understand
  - Expectations of Hispanic women
  - Importance of knowing who their clients are
  - The CLAS Guidelines/implications of Title VI
  - Know what language access resources and services are available
- How to reach providers
  - Have PCP Partners give presentations to their staff
  - Identify Hispanic physicians and nurses as spokespersons
  - Presentations at professional meetings & conferences
  - Articles on CLAS standards in newsletters for SCNA, SCMA, others

# Prioritizing Messages for Latinas

- Information and guidance on how to access and navigate the U.S. healthcare system(s)
- Patient rights and responsibilities
- Health Issues
  - Pre-Natal Care
  - Urgent Care/Emergency Care
  - Prevention and Primary Care, including access to breast and cervical cancer screening

# Partnership for Cancer Prevention Outcomes and Initiatives

- Organizational Outreach and Capacity-Building
  - SCHLHC Train the Trainer Cultural Competency Workshops
  - Best Chance Network Hispanic Outreach Worker
- Research Initiatives
  - Language for Healthcare Access (2003-2005)
  - Spanish Language for Healthcare Access (2005-2006)
  - *Iniciativa Latina contra el Cancer* (2008-2012)
  - Hispanic Health Research Network (2008-2011)
  - Navegantes para la Salud (2011-2014)



2008 – 2012

Funding:

American Cancer Society  
South Carolina Cancer Alliance

# *Iniciativa Latina Contra el Cáncer*

- Materials Assessment and Development
  - Systematic Assessment of Spanish language cancer education materials
  - Cultural adaptation of the SCCA Cancer Education Guide
- Training and support of *promotora*-led community education and screening referrals
- Evaluation of cancer knowledge and support and screening follow-up

## ASSESSMENT ACTIVITIES

- Assessment of suitability of Spanish language cancer education materials
- Cultural and linguistic adaptation of the SCCA Cancer Education Guide
  - Community Panel
  - Expert Review
- Spanish language media communications
  - Community focus groups and expert review
  - Collaboration with American Cancer Society



## Community Engagement through *Promotoras* (*Community Health Workers*)

- *Promotoras*
  - Latinas already engaged in community work (church, school, ESL classes, healthcare interpretation)
  
- Program Participants
  - Latinas, relatively young, lacked health insurance, low-income, generally with limited English proficiency

## IMPLEMENTATION/ACTIVITIES

- Tailored, community-based cancer education and outreach provided through *promotoras de salud* (trained lay community health workers)
- Individually tailored referrals for breast and cervical cancer screening
- Community-based cancer communication campaigns
  - Print media (newsletters, newspaper articles)
  - Radio (PSAs, radio call-in shows)

# Latina Initiative *Promotora* Referrals for Breast and Cervical Cancer Screening (2010-2011 Project)

| Referrals         | Best Chance Network | Health Department | Cancer Health Initiative | Free Medical Clinic | FQHC | Private Doctor | Total |
|-------------------|---------------------|-------------------|--------------------------|---------------------|------|----------------|-------|
| Mammography       | 7                   | 24                | 41                       | 0                   | 3    | 2              | 77    |
| Pap Test          | 7                   | 46                | 161                      | 0                   | 5    | 5              | 224   |
| Total Individuals | 7                   | 46                | 161                      | 0                   | 5    | 5              | 224   |

# *Promotora* Follow-Up on Participant Screening Intent and Behaviors (2010-2011)

|                         | Best Chance Network | Health Department | Cancer Health Initiative | Free Medical Clinic | FQHC | Private Doctor | Total |
|-------------------------|---------------------|-------------------|--------------------------|---------------------|------|----------------|-------|
| Appointment Assistance  | 0                   | 0                 | 14                       | 0                   | 0    | 0              | 14    |
| Confirmed Went          | 1                   | 24                | 82                       | 0                   | 4    | 1              | 112   |
| Confirmed did not go    | 1                   | 0                 | 8                        | 0                   | 0    | 0              | 9     |
| Already had appointment | 0                   | 0                 | 6                        | 0                   | 0    | 4              | 10    |
| Did not get appointment | 1                   | 10                | 30                       | 0                   | 3    | 0              | 44    |
| No response             | 1                   | 12                | 21                       | 0                   | 1    | 0              | 35    |
| Total Follow-up         | 4                   | 46                | 161                      | 0                   | 8    | 5              | 224   |

# Pre and Post Test Cancer Knowledge Survey Results

## 2010-2011(n=219)

| Question            | 1    | 2    | 3    | 4    | 5    | 6    | 7    | 8    | 9    | 10   | Mean % |
|---------------------|------|------|------|------|------|------|------|------|------|------|--------|
| % Correct Pre-Test  | 24.2 | 39.9 | 62.4 | 63.4 | 18.7 | 78.6 | 45.3 | 11.9 | 31.4 | 57.8 | 43.4   |
| % Correct Post-Test | 96.2 | 89.6 | 88.6 | 96.2 | 91.3 | 97.4 | 98.3 | 74.5 | 88.7 | 83.7 | 90.4   |
| Pre-Post Change     | 72.0 | 49.6 | 26.1 | 32.9 | 72.5 | 18.8 | 53.0 | 62.6 | 57.3 | 25.9 | 47.1   |

## Ongoing barriers to breast and cervical cancer screening

- Language and communication barriers (difficulty making telephone appointments and understanding messages from providers)
- Family and workload demands
- Lack of transportation
- Conflicting information about cost and access
- Feelings of discrimination/fear due to increasing anti-immigrant public policies and practices

## Successes

- Increased involvement and social support from *promotoras* and some providers

# **Engaging Provider Partners in Research: Hispanic Health Research Network (HHRN)**

**2008-2011**

**Funding**

**NIH/NCI Partners in Research Program**

**1R03HD059550-01**

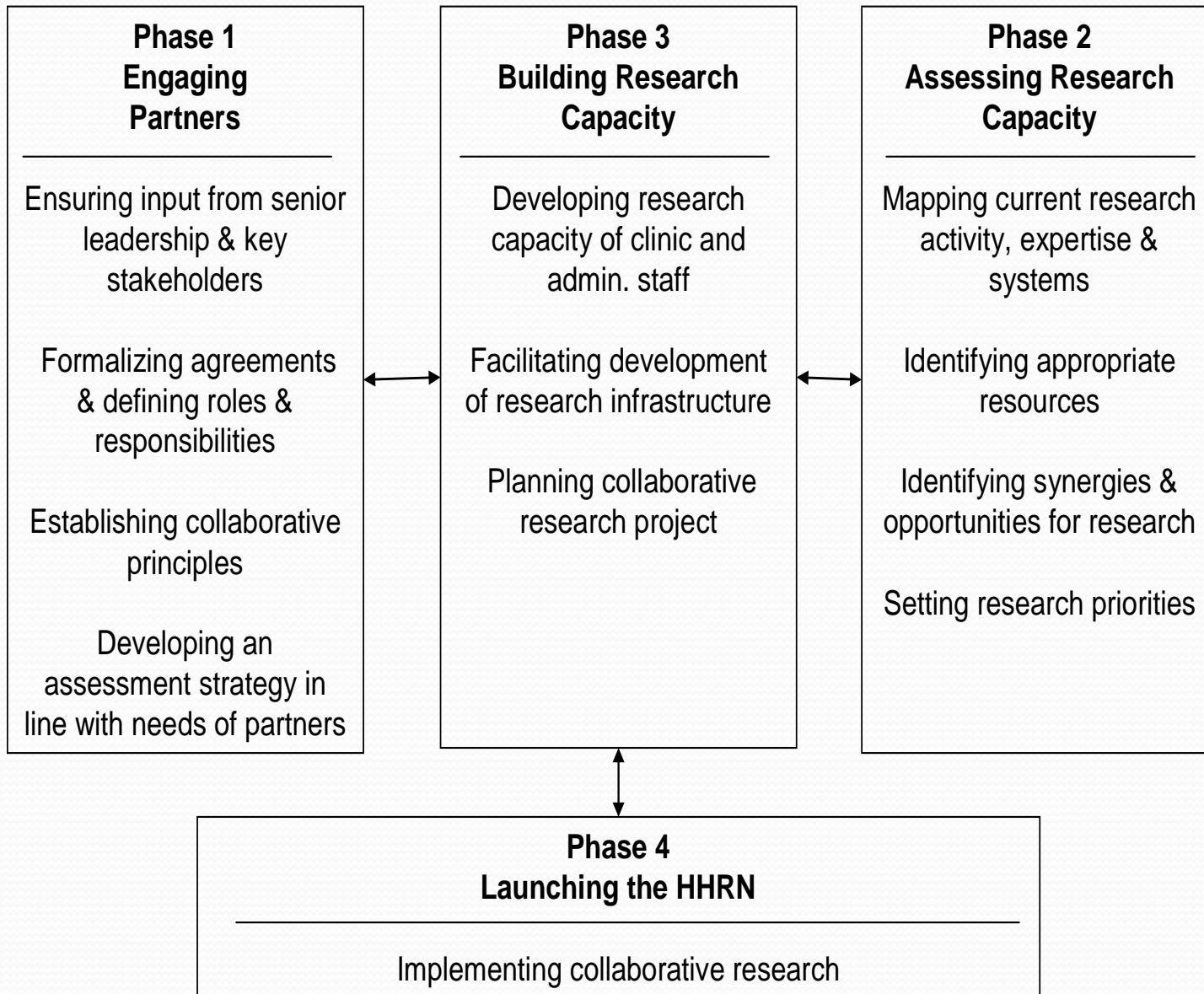
# **Engaging Provider Partners in Research: Hispanic Health Research Network (HHRN)**

- Collaboration between the South Carolina Hispanic/Latino Health Coalition, USC, and 3 local providers:
  - Palmetto Health Women's Center
  - Eau Claire Cooperative Health Centers
  - The Community Medical Clinic of Kershaw County
- Funded through NIH/NCI Partners in Research Program 1R03HD059550-01 (2008-2011)

# Hispanic Health Research Network

- Specific Aims:
  - To **enhance existing community-academic research partnerships** by actively engaging professionals and support staff of local primary care practices in the formation of a **Hispanic health research network (HHRN)** that will address health care disparities research among the emerging Latino population.
  - To **assess the organizational Hispanic health research capacity** of primary care practices that provide breast and cervical cancer (BCC) screening to Latinas.
  - To **build the Hispanic health research capacity** of primary care providers, staff, and organizations.

## Figure 1: HHRN Project Model



# HHRN Phase 2: Formative Assessments

- Review of materials, on-site interviews and observations
- Major themes related to clinical partner research interests
  - Improving service delivery for Hispanic clients
  - Analyzing existing data on Hispanic clients
  - Examining utilization and effectiveness of language interpretation services
  - Determining health literacy levels and providing culturally and linguistically appropriate health education materials
  - Sharing research and practice policies and guidelines (e.g. Spanish-language documents)
  - Enhancing exchange of information and experiences among practice-based partners

# HHRN Phase 3: Building Research Capacity

- Data-Use Agreements in place with all clinical partners
- Creating a baseline “snap-shot” of Hispanic patients in 2009
  - Age
  - Gender
  - Diagnostic Codes
  - Procedure Codes
  - Provider
  - Language/Interpreter Services

# HHRN Collaborative Research Outcome:

## *Navegantes para Salud*

A research partnership with  
Eau Claire Cooperative Health Centers  
2011 - 2015

Funding:  
Centers for Medicare and Medicaid Hispanic Health Services  
Research Grant Program

## *Navegantes para Salud : Research Aims*

- To develop, implement, and test the effectiveness of a culturally and linguistically appropriate bilingual patient outreach and navigational support service intervention within the context of a federally qualified health center.

# NPS Intervention

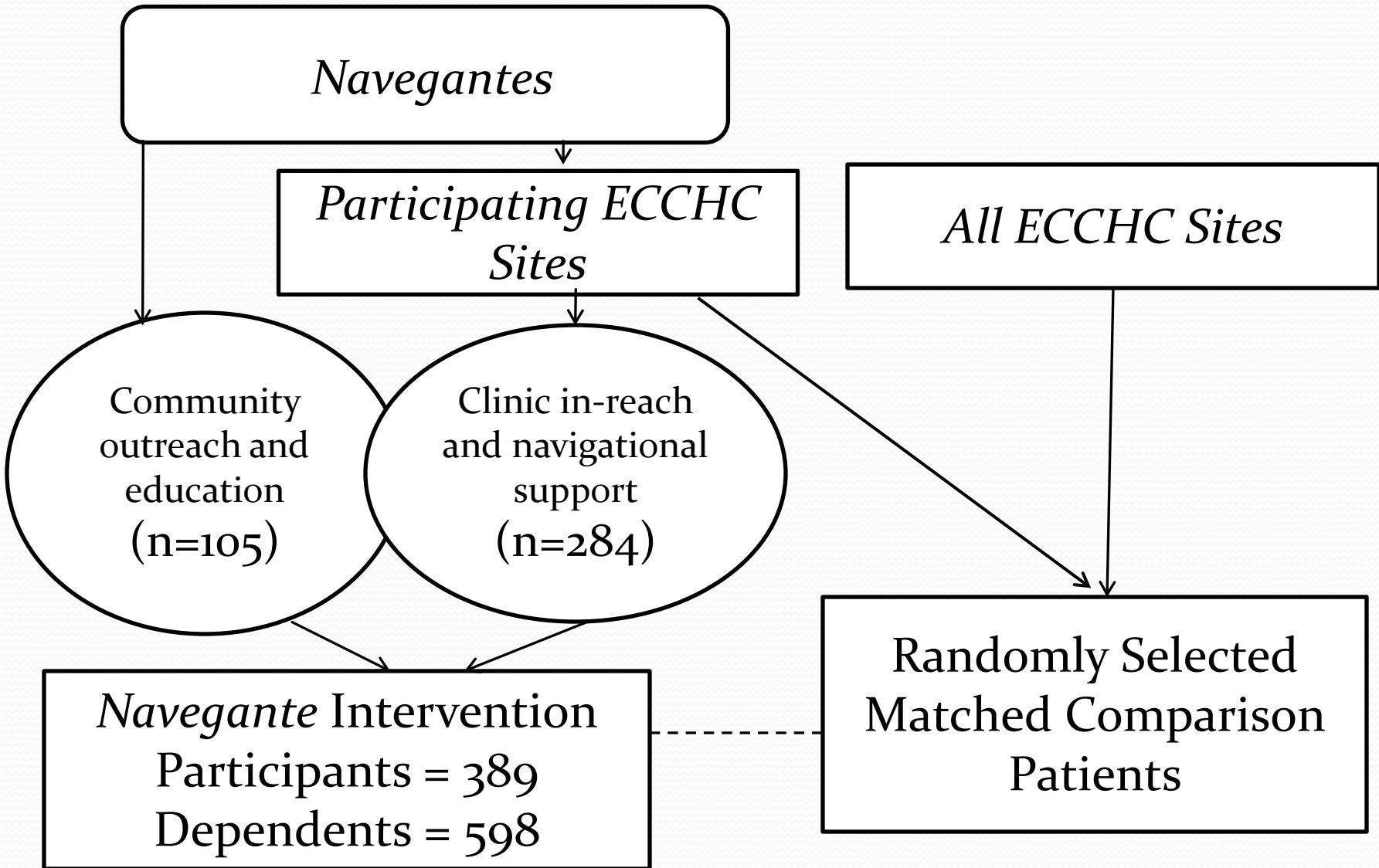
- Innovative hybrid community health worker/patient navigator model with goal of improving access and utilization of community health clinics among Hispanic women and their children
- Outreach and education about U.S. healthcare system(s)
- Onsite navigational assistance (e.g., Medicaid enrollment, appointment reminders and follow-up, specialty clinic referrals, pre-delivery hospital tours).

# Process Evaluation: Navigator Activities

- Medicaid Application Assistance (n=256)
- Appointment assistance (n=163)
- Referrals to other programs/resources (n=133)
- Assistance completing forms (n=106)
- Dental referrals and assistance (n=74)
- Hospital registration assistance (n=71)
- Newborn Medicaid Application (n=66)
- Assistance with WIC appointments (n=60)
- Medicaid transportation assistance (n=43)
- Follow-up OB/GYN appointments (n=35)
- Benefit Bank application assistance (n=33)
- Hospital Labor and Delivery tours (n=18)
- Home visits (n=17)

# *Navegantes para Salud*

## Research Design



# Ongoing Issues and Opportunities for Research with Latinas in South Carolina

- Healthcare access and utilization
  - Women's health care
  - Family health care
  - Language assistance and cultural competency
  - Health care navigation strategies
- Health impact of patterns of social incorporation and social marginalization on health and health care access
- Tracking demographic and epidemiological trends

# Lessons Learned

- Engage with diverse partners – and start with them where they are
- Build on existing networks and structures
- Share information and resources
- Be persistent and committed for the long haul
- Maintain and sustain relationships even through difficult economic and political times
- Be ready to pass the baton and develop a succession plan ☺

¿Preguntas?  
Perguntas?  
Questions?  
**DISCUSSION!**