

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

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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

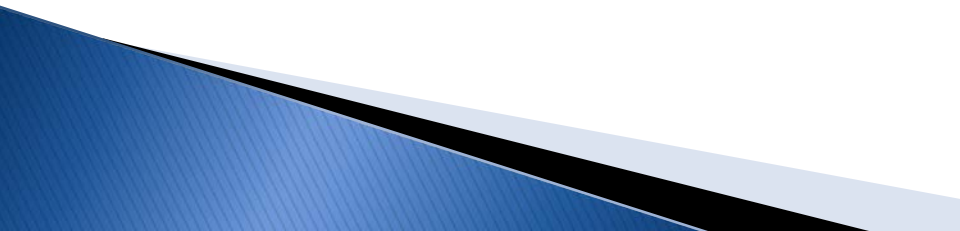
➤ 1990 – 2000 – **211.2% increase**

➤ County rates ranged from low of 12.4% (Allendale)
to 1,624.% (Jasper County)

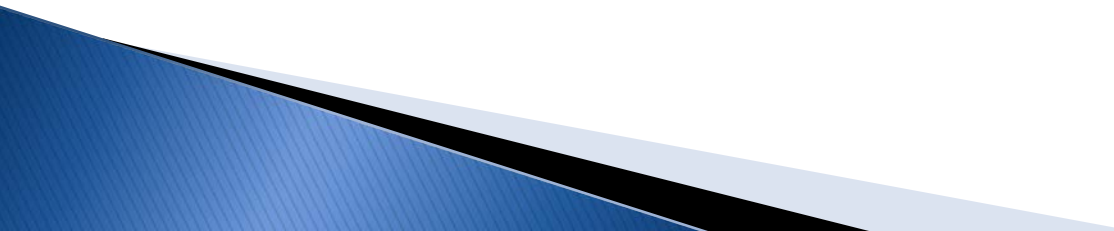
➤ 2000 – 2011 – **154% increase**



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
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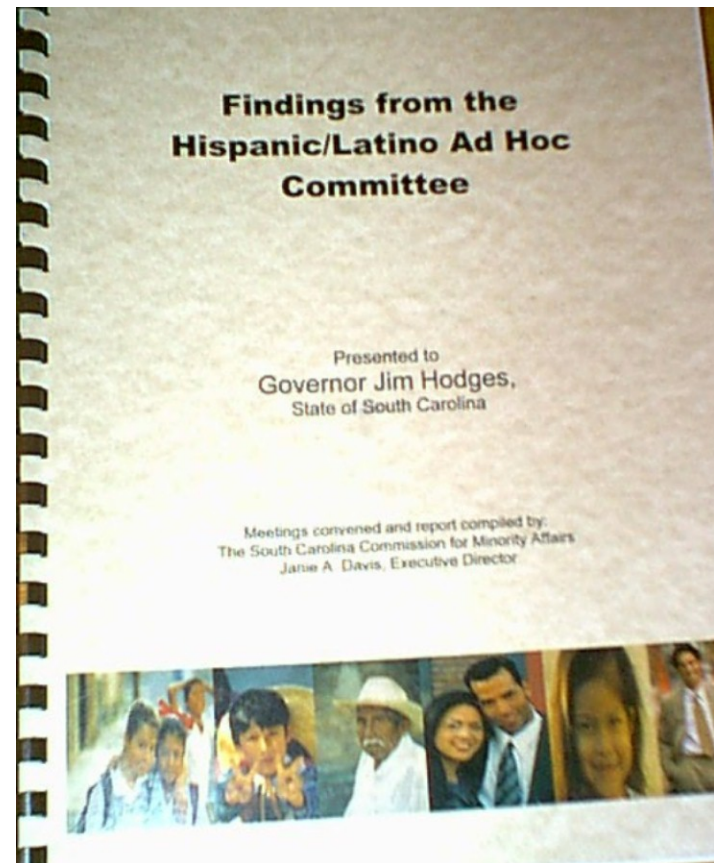
Health Subcommittee Process: Engaging the Community

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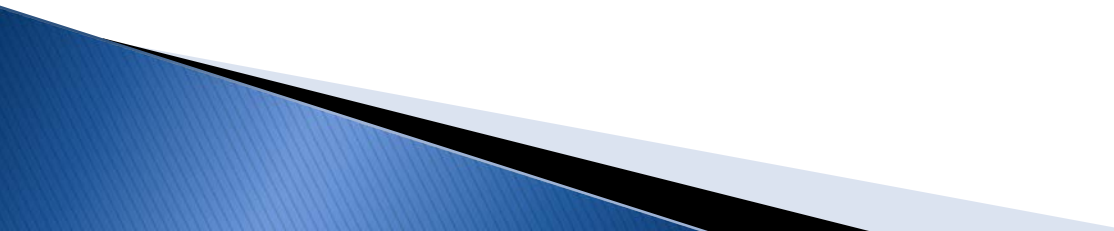
Health Subcommittee Findings

Hispanic Health Issues and Concerns

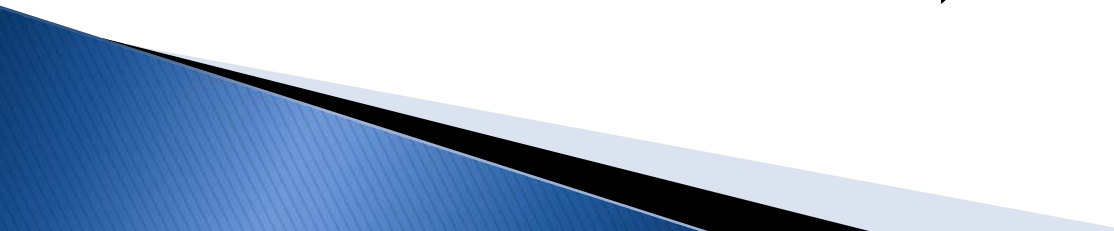
- Language and communication barriers
- Cultural competency (*mutual competency*)
- Access to care barriers (*cost, insurance, transportation*)
- Lack of data for planning & surveillance
- Immigration and social issues (*documentation; discrimination*)



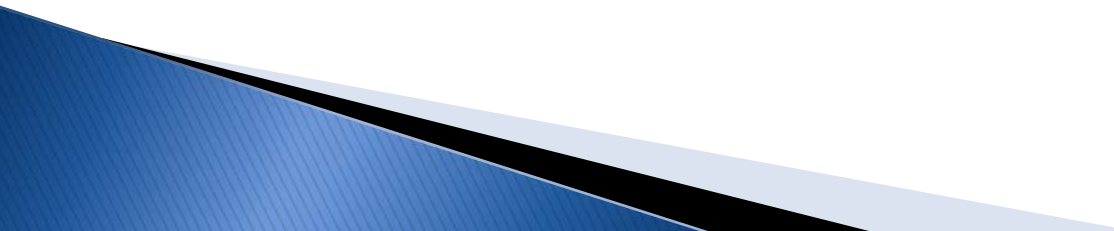
Challenges/Underlying Issues

- ▶ 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
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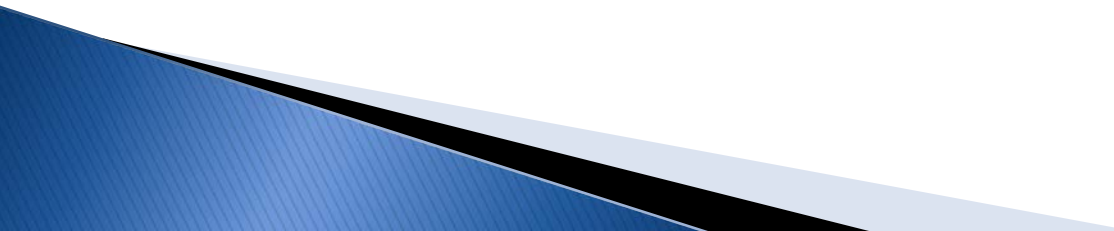
Outcomes of the Health Subcommittee Process

- ▶ 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)
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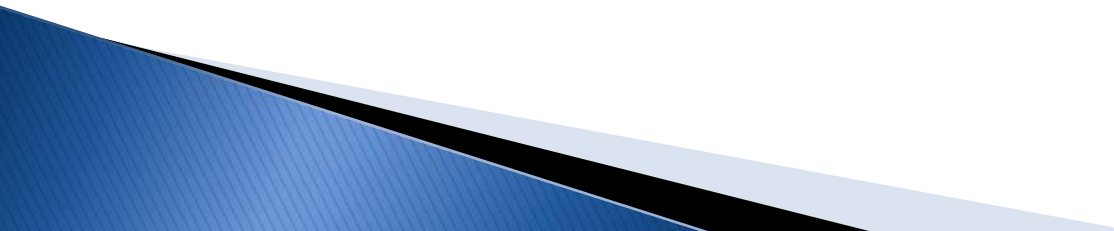
SCHLHC Mission

- ▶ 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).
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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.
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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.
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SCHLHC/USC Community
Engaged Research
Collaborations
2001–2014



Redes En Acción



The National Hispanic/Latino Cancer Network

South Carolina Partnership for Cancer Prevention

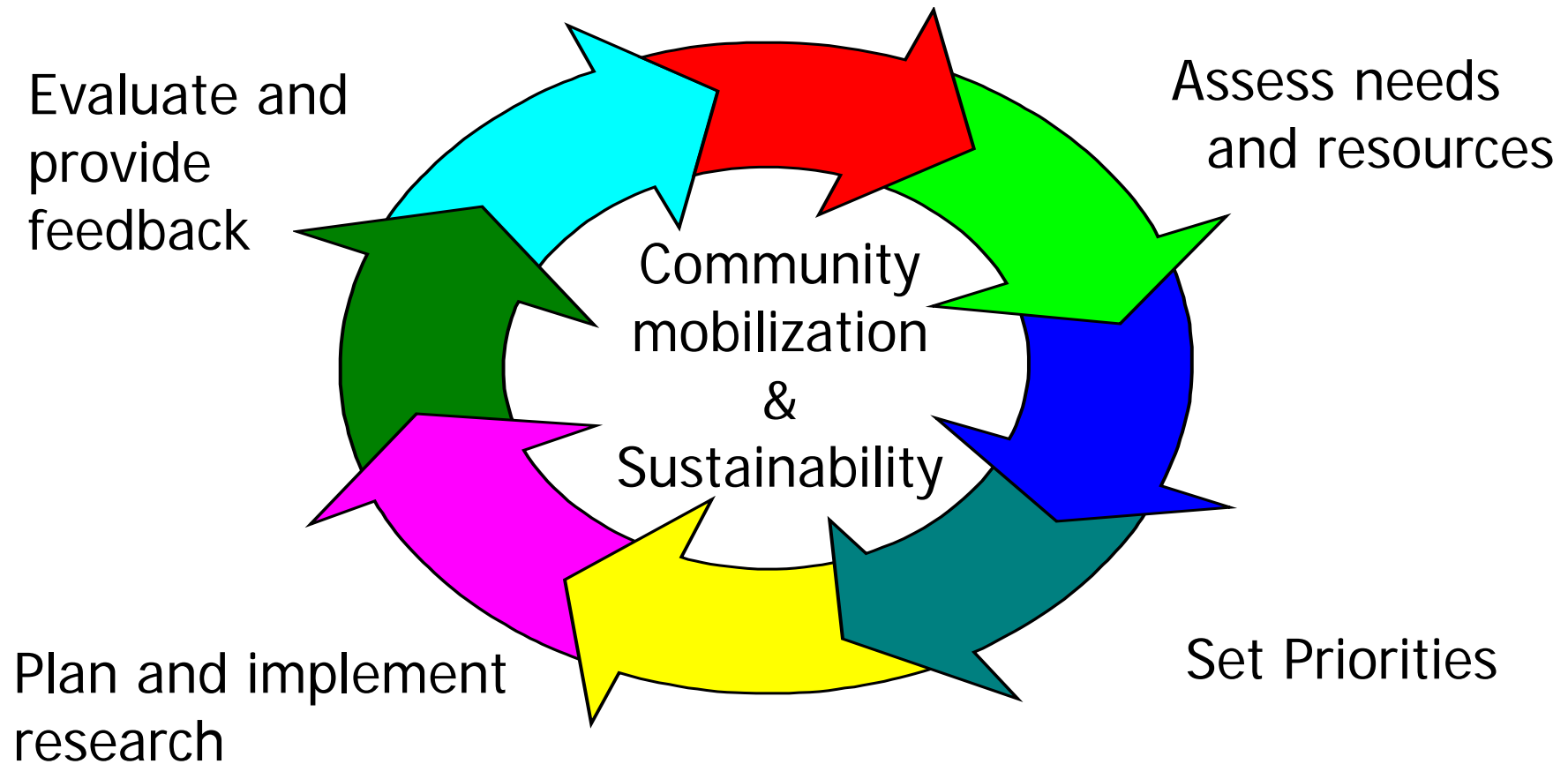
- ▶ First SCHLHC community-based participatory research partnership (2001–2002)
- ▶ Funded through National Cancer *Institute/Redes En Acción National Hispanic/Latino Cancer Network*



**Redes
En Acción**



Community Partnered Research






**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
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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* (2008-20012)
 - 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

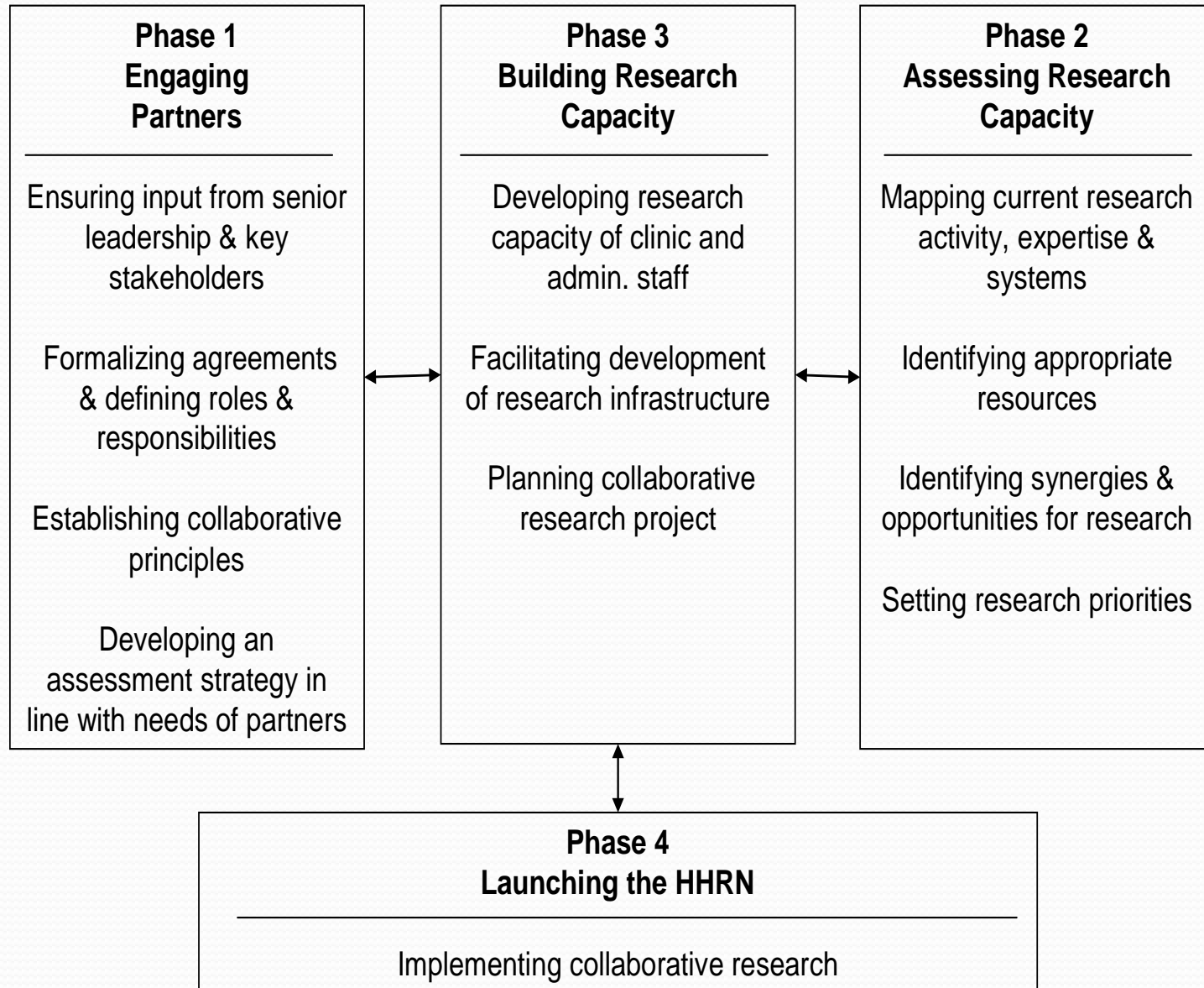
Engaging Provider Partners in Research: Hispanic Health Research Network (HHRN)

- 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

Navegantes

*Participating ECCHC
Sites*

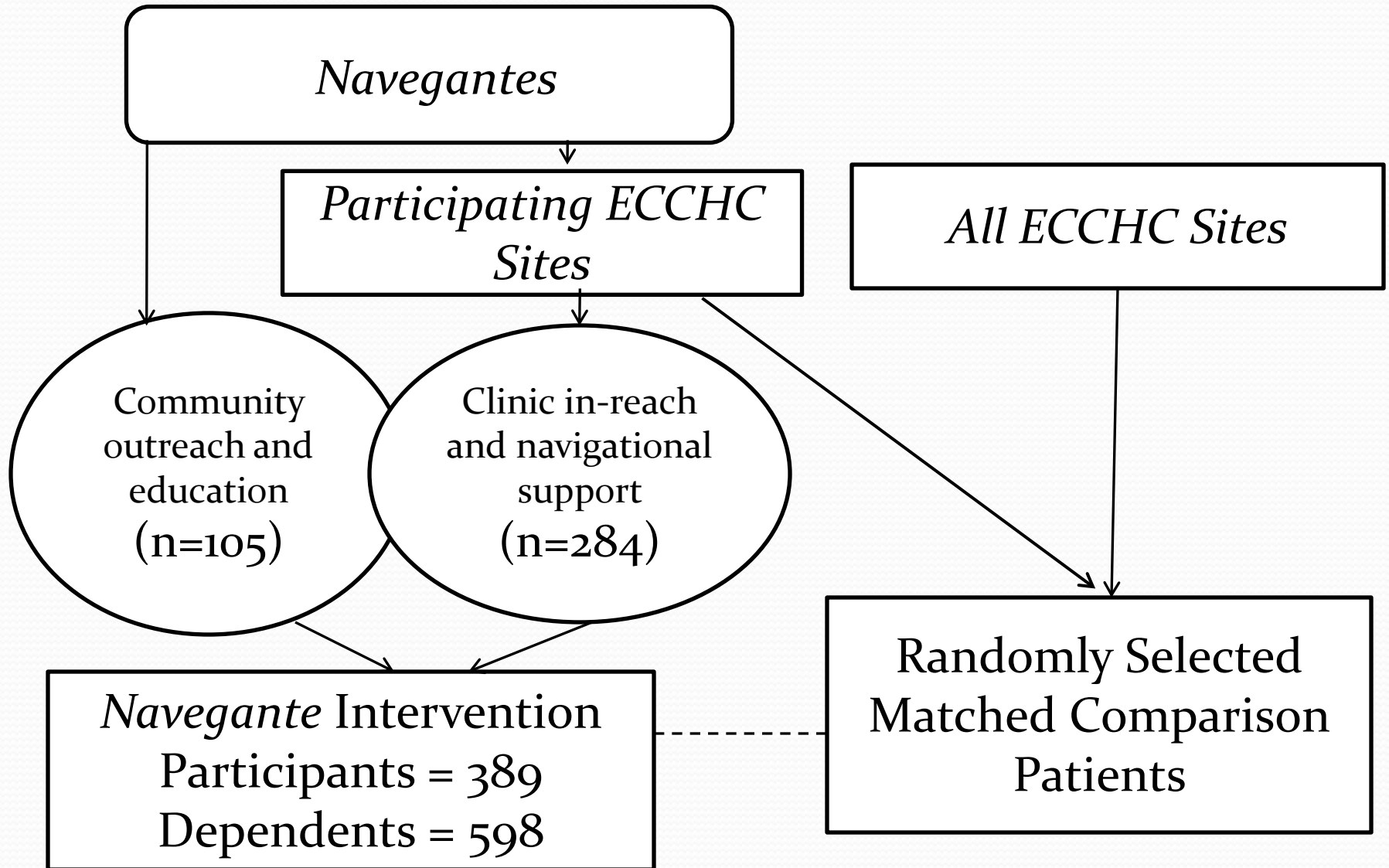
All ECCHC Sites

Community
outreach and
education
(n=105)

Clinic in-reach
and navigational
support
(n=284)

Navegante Intervention
Participants = 389
Dependents = 598

Randomly Selected
Matched Comparison
Patients




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!