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

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>1990</td>
<td>30,551</td>
<td>1.1</td>
</tr>
<tr>
<td>2000</td>
<td>96,178</td>
<td>2.3</td>
</tr>
<tr>
<td>2010</td>
<td>235,682</td>
<td>5.1</td>
</tr>
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</table>

- **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
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)
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
South Carolina Partnership for Cancer Prevention


- Funded through National Cancer Institute/Redes En Acción National Hispanic/Latino Cancer Network
Community Partnered Research

Set Priorities
Plan and implement research
Assess needs and resources
Community mobilization & Sustainability
Evaluate and provide feedback
 Gemeunity Partnered Research
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
  - 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)

<table>
<thead>
<tr>
<th>Referrals</th>
<th>Best Chance Network</th>
<th>Health Department</th>
<th>Cancer Health Initiative</th>
<th>Free Medical Clinic</th>
<th>FQHC</th>
<th>Private Doctor</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammography</td>
<td>7</td>
<td>24</td>
<td>41</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>77</td>
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<tr>
<td>Pap Test</td>
<td>7</td>
<td>46</td>
<td>161</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>224</td>
</tr>
<tr>
<td>Total Individuals</td>
<td>7</td>
<td>46</td>
<td>161</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>224</td>
</tr>
</tbody>
</table>
## Promotora Follow-Up on Participant Screening Intent and Behaviors (2010-2011)

<table>
<thead>
<tr>
<th></th>
<th>Best Chance Network</th>
<th>Health Department</th>
<th>Cancer Health Initiative</th>
<th>Free Medical Clinic</th>
<th>FQHC</th>
<th>Private Doctor</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appointment Assistance</strong></td>
<td>0</td>
<td>0</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>14</td>
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<tr>
<td><strong>Confirmed Went</strong></td>
<td>1</td>
<td>24</td>
<td>82</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>112</td>
</tr>
<tr>
<td><strong>Confirmed did not go</strong></td>
<td>1</td>
<td>0</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
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<tr>
<td><strong>Already had appointment</strong></td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>10</td>
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<tr>
<td><strong>Did not get appointment</strong></td>
<td>1</td>
<td>10</td>
<td>30</td>
<td>0</td>
<td>3</td>
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<td>21</td>
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<tr>
<td><strong>Total Follow-up</strong></td>
<td>4</td>
<td>46</td>
<td>161</td>
<td>0</td>
<td>8</td>
<td>5</td>
<td>224</td>
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## Pre and Post Test Cancer Knowledge Survey Results 2010-2011 (n=219)

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Mean %</th>
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</thead>
<tbody>
<tr>
<td>% Correct Pre-Test</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pre-Test</td>
<td>24.2</td>
<td>39.9</td>
<td>62.4</td>
<td>63.4</td>
<td>18.7</td>
<td>78.6</td>
<td>45.3</td>
<td>11.9</td>
<td>31.4</td>
<td>57.8</td>
<td>43.4</td>
</tr>
<tr>
<td>% Correct Post-Test</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Test</td>
<td>96.2</td>
<td>89.6</td>
<td>88.6</td>
<td>96.2</td>
<td>91.3</td>
<td>97.4</td>
<td>98.3</td>
<td>74.5</td>
<td>88.7</td>
<td>83.7</td>
<td>90.4</td>
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<tr>
<td>Pre-Post Change</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>72.0</td>
<td>49.6</td>
<td>26.1</td>
<td>32.9</td>
<td>72.5</td>
<td>18.8</td>
<td>53.0</td>
<td>62.6</td>
<td>57.3</td>
<td>25.9</td>
<td>47.1</td>
</tr>
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</table>
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.
Phase 1: Engaging Partners
- Ensuring input from senior leadership & key stakeholders
- Formalizing agreements & defining roles & responsibilities
- Establishing collaborative principles
- Developing an assessment strategy in line with needs of partners

Phase 2: Assessing Research Capacity
- Mapping current research activity, expertise & systems
- Identifying appropriate resources
- Identifying synergies & opportunities for research
- Setting research priorities

Phase 3: Building Research Capacity
- Developing research capacity of clinic and admin. staff
- Facilitating development of research infrastructure
- Planning collaborative research project

Phase 4: Launching the HHRN
- Implementing collaborative research

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**

- Community outreach and education (n=105)
- Clinic in-reach and navigational support (n=284)

**Navegante Intervention Participants** = 389
Dependents = 598

**All ECCHC Sites**

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!