

# Participatory Action Research: The SC Partnership for Cancer Prevention



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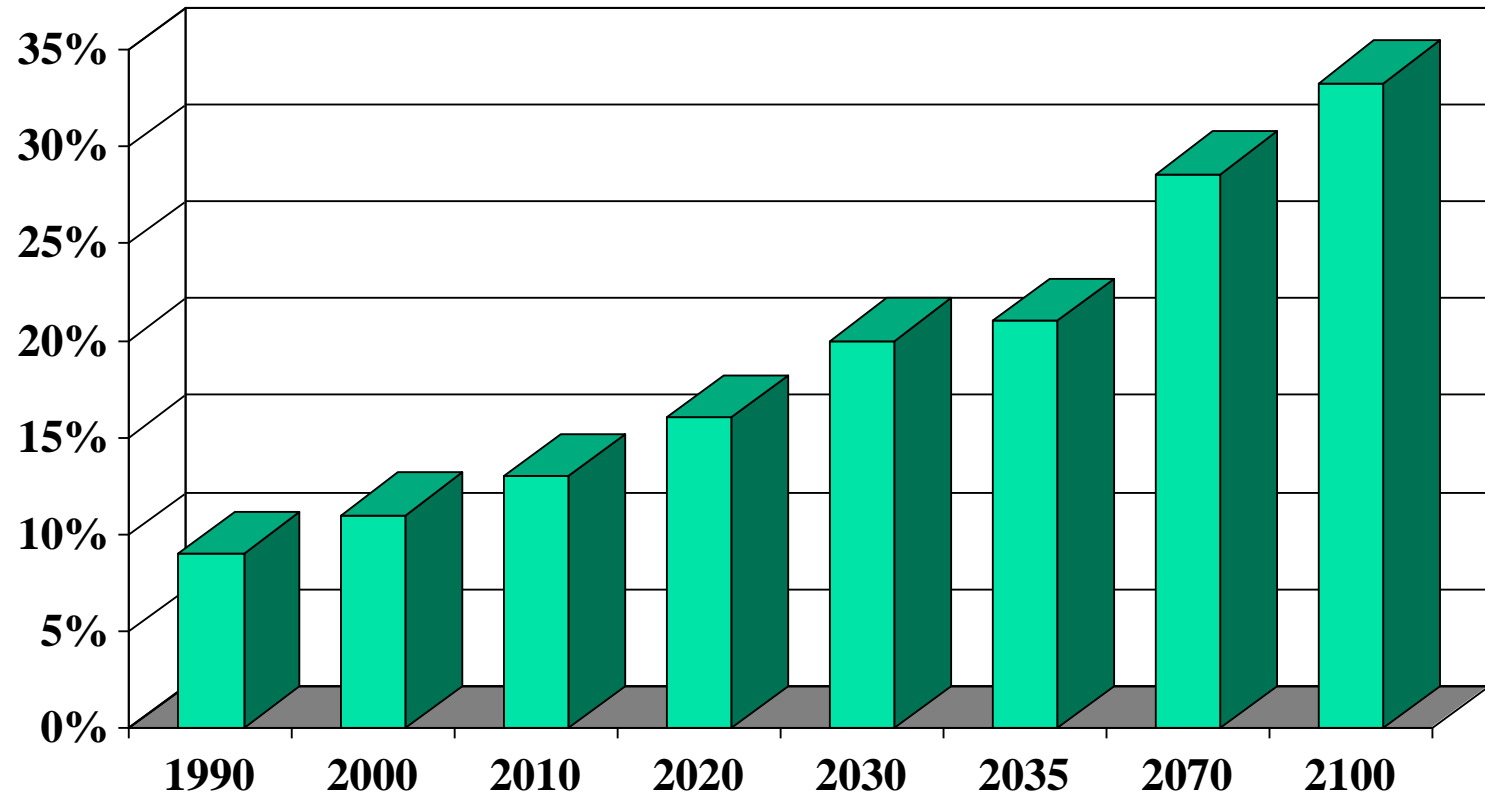
# Hispanics in the United States

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- 35.3 Million Hispanic/Latinos in the US
- 12.5% of Total U.S. Population
- This does not take into account:
  - 3 to 6 million undocumented workers
  - 3.8 million persons in the island of Puerto Rico
- Between 1990-2000
  - Total US population grew by 13.2%
  - Hispanic population grew 57.9%



# U.S. Hispanic Population 1990-2100



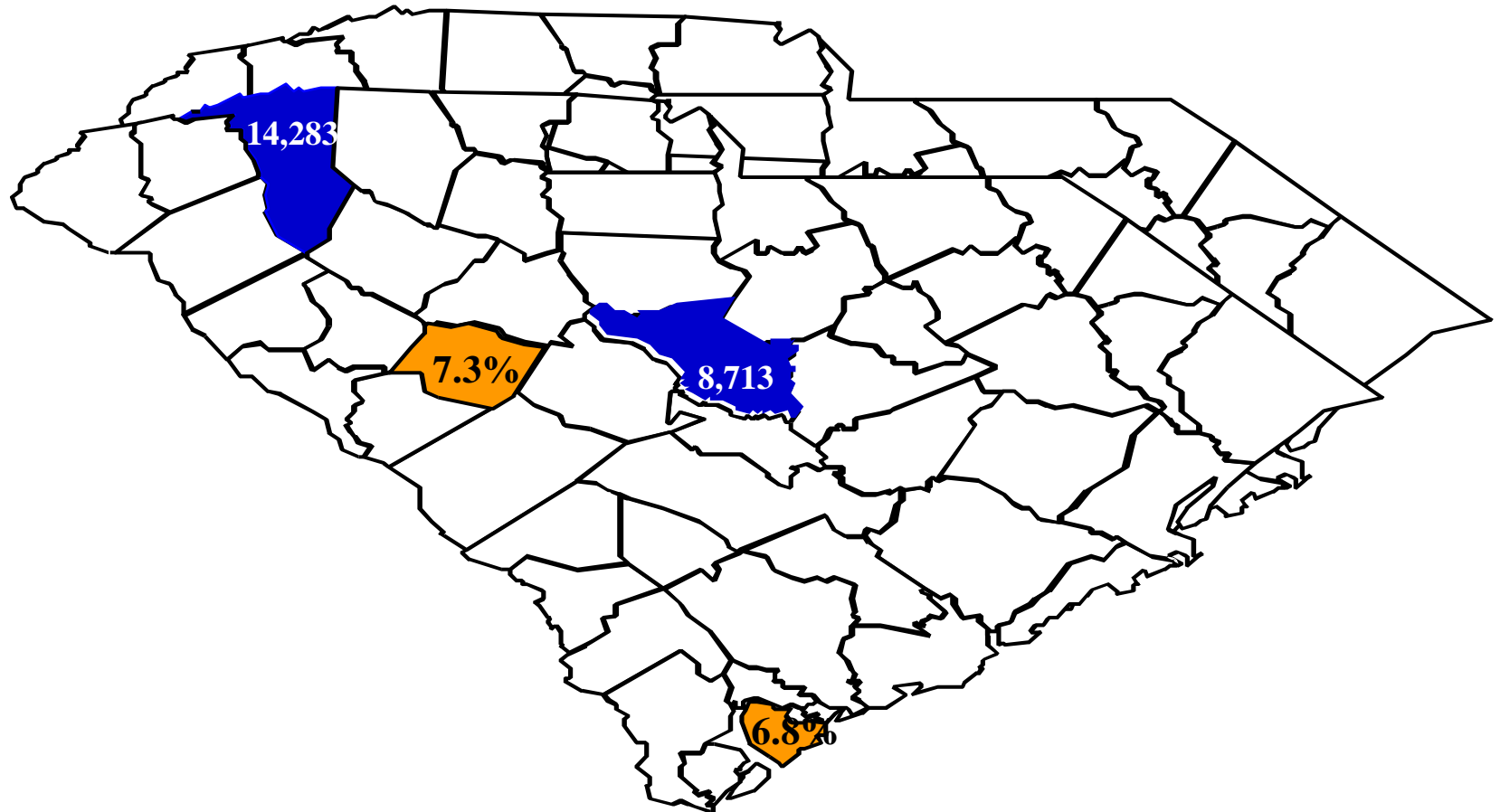
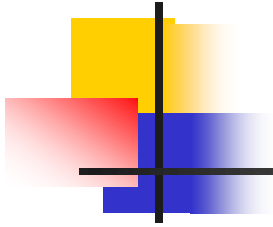


# Population Growth

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- Latino population more than tripled in six southern states (1990-2000)
  - Alabama, Arkansas, Georgia, Tennessee, North Carolina, & South Carolina
- South Carolina Latino population
  - 1990 (30,551) - 2000 (95,076)
  - Counties with highest concentration
    - Saluda (7.3%) and Beaufort (6.8%)
  - Counties with largest populations
    - Greenville (14,283) and Richland (8,713)

# South Carolina's Latino Population



# SC Latino community characteristics



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- Limited-English-proficient Latinos
  - Average age -- 30 years, Median age – 28 years
  - 75% employed
  - 87% uninsured
  - Average years in US -- 3 years
  - 93% Mexican origin
  - 79% speak only Spanish



# SC Partnership

## Historical Context

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- 1. Governor's Office Identifies & Prioritizes Hispanic LEP Issues
  - *Health Issues Sub-Committee*
- 2. Hispanic /Latino Health Coalition
- 3. Pilot – Redes En Accion (*The Action Network*)

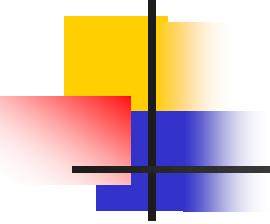
# Governor's Office

## Hispanic/Latino Ad-hoc Committee



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- Identify barriers to delivery of services to non-English speaking Hispanic/Latino population in SC and advise the Governor
- Staffed by Commission of Minority Affairs and Office of the Governor (July 2000)
- 5 subcommittees
  - Education
  - Health Care
  - Public Safety (emergency preparedness, police and emergency services, legal system)
  - Human rights (workers rights, civil rights, housing)
  - Immigration/Transportation/Fraud



# Governor's Office

## Health Issues Sub-committee

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- Over 50 persons representing
  - Health Department, Mental Health, CBOs, University, Hospitals, Clinics, Social Services, Insurance
- Health Priorities
  - language barriers
  - cultural competency
  - barriers to service (*cost, insurance, transportation*)
  - lack of data for planning & surveillance
  - immigration and social issues (*lack of documentation & discrimination*)
- Recommendations



# Recommendations

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- Implementation of National Standards on Culturally and Linguistically Appropriate Services (CLAS in Health Care and Executive Order 13166 (LEP) [www.omhrc.gov/CLAS](http://www.omhrc.gov/CLAS)
- Education, training, capacity assessment, implementation
- Hispanic Health Data
- Collaboration



# SC Hispanic/Latino Health Coalition

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- 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 align with the guidelines set forth by the National Health Care Standards for Culturally and Linguistically Appropriate Services (CLAS).

# SC Hispanic/Latino Health Coalition Objectives



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- To **improve communication** among health care service providers, state agencies, and the Hispanic/Latino community.
- To **reduce** organizational, systemic, and cultural **barriers** to health care.
- To **promote** “best practices” and **cultural competency** by agencies and organizations across South Carolina.
- To **foster collaborative efforts and partnerships** around specific issues of concern to the Hispanic/Latino population in South Carolina.
- To serve as a **liaison** and **advisor** to public and private agencies and organizations.



# Meanwhile.....

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Redes En Accion releases an RFA for  
Pilot projects

➤ *Partnership for Cancer Prevention is conceived*



# Pilot Studies RFA

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- Latino Investigators focusing on cancer related issues of Latino populations
- Research Career Development
- Pilot data for R01 type grant
- \$50,000 total for 1 year
- Mentoring and support from network



# Resources

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- Special Populations Networks
  - (RFA CA-99-003)
- Redes en Accion Newsletters/Website
- Pilot Application/Evaluation Criteria
- SERCAC Minutes and Report 2/01
  - South Carolina priorities
  - Regional recommendations



# Key Concepts

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- Access to cancer screening and care
- Doctor/Patient or Risk Communication
- Cervical cancer\*\*
- Community based organizations and Research organization Partnerships
- Health disparities
- Participatory research



# Cervical Cancer

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- Latinas have a higher incidence and mortality rate for cervical cancer than non-Hispanic white women.
  - Mexican-American and Puerto Rican women incidence rates 2-3 times higher
  - Especially high in 1<sup>st</sup> generation/ immigrants
    - Higher rates of HPV
- South Carolina
  - 8<sup>th</sup> highest in Cervical cancer mortality
  - 1<sup>st</sup> in several STDs (chlamydia, gonorrhea)
  - No state data on HPV



# Cervical Cancer

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- Secondary Prevention
  - Low utilization of Pap tests by Latinas
    - Over 50% reported not having a Pap test in the last year
    - 82% past 3 years
    - In SC 75% of LEP Latinas report “ever” having pap
- Primary Prevention
  - Lower personal risk reported among Latina immigrants
    - Influence of male partner needs further study

# Levels of Partnerships

Organization	Definition	Structure
Network	The set of linkages among people or organizations. Network structure may have effects on the behavior of the members -- <i>**Exchange of Information**</i>	Organizationally loose and very flexible. Perhaps an initial step towards other structures
Coordination	Exchanging information and <i>altering activities for mutual benefit to avoid duplication of effort</i>	Incorporates elements of other's organizational activities into their own
Coalition	An organization of individuals representing diverse organizations, functions, or constituencies <i>who agree to work together in order to achieve common goal</i>	Additional structural strength and longevity with some effects on each organization's actions. Perhaps a limited time period.
Partnership	A more enduring and highly structured organization of diverse groups <i>working together to achieve multiple goals over time.</i>	A well organized, differentiated structure with great longevity



# Disparities

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- Health Status
- Access to Health Care
- Populations defined on the basis of
  - Race or ethnicity
  - Underserved
- Reflect or result from societal systems of oppression
  - Race, class, gender and sexuality



# With Disparities in the equation

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- Partnerships must share power
- Researchers must deliver benefits to the community
- Projects must be sustained over time



# Participatory Research

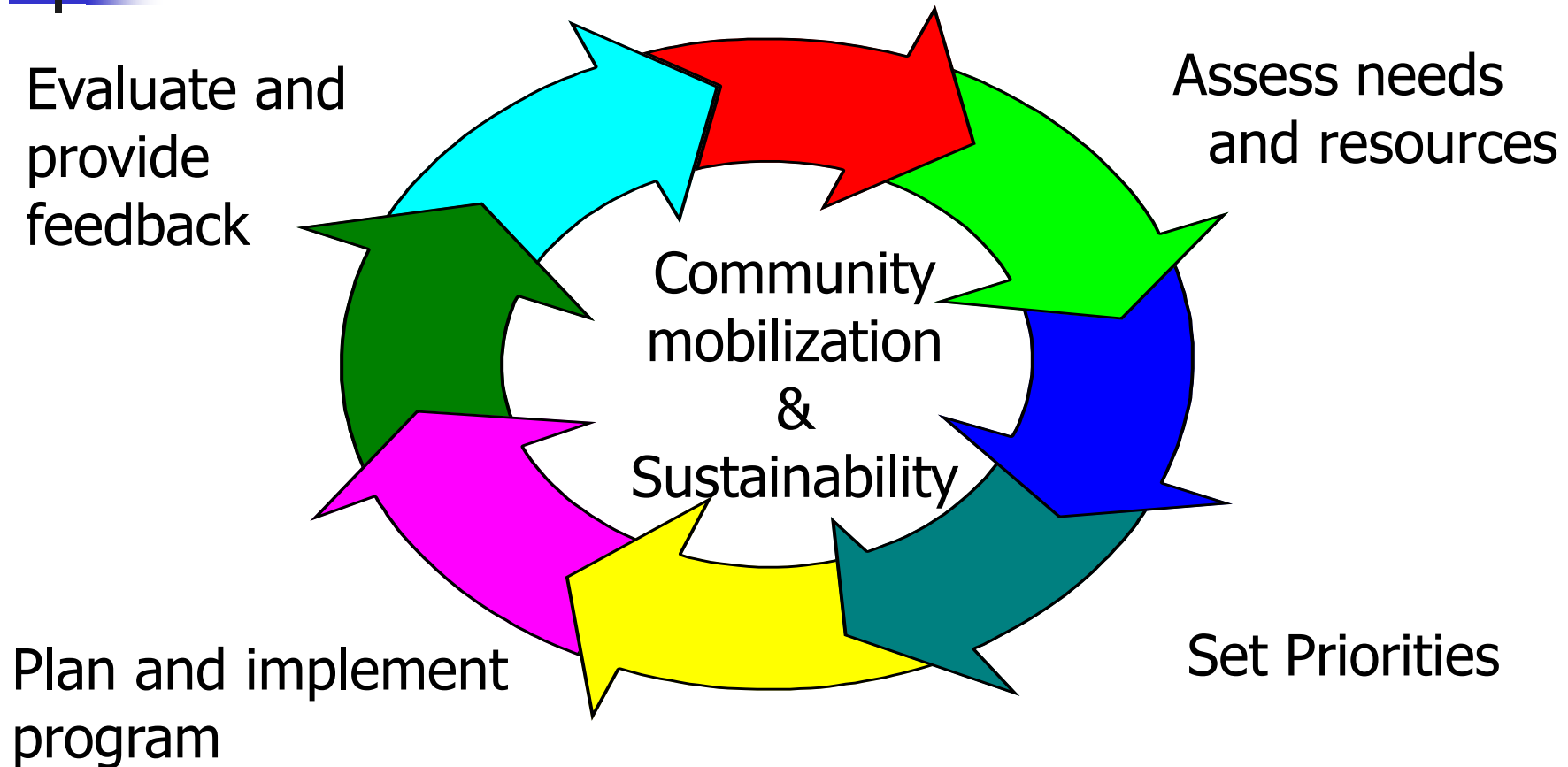
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- Approach that involves researchers, practitioners and community as equal partners in conceptualizing and conducting research
- Cyclical problem-solving process
- Combines research, education and social action
- Utilizes both qualitative and quantitative methods



# Community Partnered Research

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# Aim 1: Community Partnership Development

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- To build Hispanic/Latino partnerships and community capacity in South Carolina.
  - Use participatory research to foster the development of the SCPCP by promoting partnerships b/w SCHHC, CBOs, state agencies and USC to
  - address Hispanic cancer issues, specifically cervical cancer prevention and detection



# Aim 2: Formative Message Development

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- To further understanding of the intersections of gender, ethnicity, class and other power inequalities as they relate to attributes and behaviors around cervical cancer prevention and detection among Hispanic/Latino women and men
- explorative qualitative approach
- formative research on message development



# Methodology

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- Two levels of focus
  - organizations and systems (partnerships, community capacity)
    - “community” based planning
    - empowerment evaluation
  - Latino community (health ed., message development)
    - focus groups (men, women, married, unmarried)



# Partners

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- Hispanic/Latino Health Coalition
- Best Chance Network (SC-BCCEDP: DHEC & ACS)
- Universities: USC & Clemson
- Hispanic Outreach
- HABLA (Interpreter Hotline)
- Immigrant Community Access Point
- Women's Health Program (DHEC & WCC)
- Family Planning Services (DHEC)
- Central Cancer Registry
- CommunityCare
- CIS



# What will we get from this?

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- Develop and maintain community partnerships for health promotion, cancer risk reduction and improved access to care
- Understanding of cancer programs and resources currently available to Latinas in SC
- Develop interventions to increase the capacity of health care systems
- Serve as groundwork for developing a grant proposal for a larger community based intervention
- Act as role model
- Create public health practice standard for sustainable & successful partnerships



# Partnership Benefits

## *To Date*

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- ✓ Broadened scope and reach: Inclusion of breast cancer
- ✓ Identified additional key community partners: CIS, Community cancer screening program
- ✓ Mobilizing resources towards the growth of partnership: ACS funding opportunity; BCN program funding