

# **Ethno-Cultural Barriers to Health Literacy and Disease Management Among African-Americans (AAs) in South Carolina**

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## **Project DIABETES**

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# South Carolina

## • Fast Facts about SC

**Population:** (2014 Census)

4.832 Million

- 63% Non-Hispanic White
- 27.8 % African American
- 5.4 % Hispanic/Latino

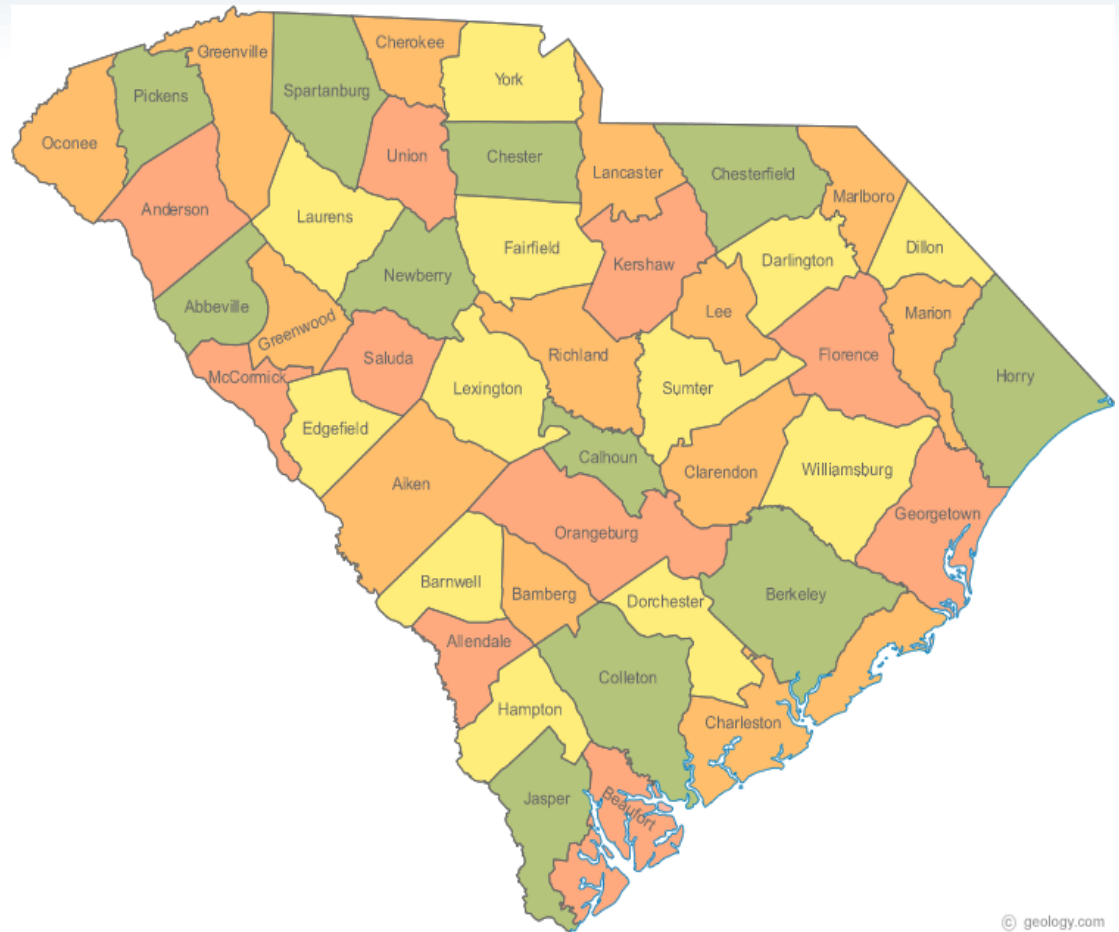
**Diabetes:** 43 counties have Diabetes rate above 7% and 3 have rates of 13%

**Obesity Rate:** 32.1%

**Statewide Adult Literacy Rate:**  
14.5%

**Graduated from High School:**  
84.5

**Percent Below Poverty** 18.1%



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# Diabetes

- Currently affects over 28 million adults in US <sup>6,7</sup> ,
- In South Carolina, 1 in 8 African Americans (AAs) have T2DM<sup>6</sup> ,
- Managed through complex medication regime, physical activity, diet & lifestyle changes, that often exclude family members,
- Adherence may be linked to culture, illness perception and low Health Literacy (HL)<sup>5</sup> ,

# Background

## Definition of Health Literacy

- The degree to which individuals have the capacity to obtain, process, understand and act on health information and services needed to make appropriate health decisions<sup>1</sup> ,
- Influenced by cognitive skills, extended families, multiple systems, culture and social determinants of health<sup>2</sup> ,
- Encompasses access to health information, capacity to use it, critical to empowerment and improving health outcomes<sup>3</sup> ,

# Why Health Literacy Matters

- People with low HL and chronic diseases, especially diabetes, self-report their health to be poorer than do those with higher HL levels<sup>3</sup> ,
- 90 million (47%) US adults cannot accurately and consistently locate, match, and integrate information from newspaper, advertisement or forms<sup>9</sup> ,
- 52% of SC residents cannot accurately and consistently integrate information from newspaper, <sup>9</sup>

# Importance of our Study

- Few studies have incorporated a cross-cultural approach, to address poor/low health literacy and chronic diseases across heterogeneous racial/ethnic populations,
- Fewer seek to explore cultural variation among AAs from other geographical regions, for their trusted sources and preferred format for seeking health information,
- Utilize a cross-cultural approach to identify contextual meanings and interpretations of diabetes as an illness among 4 distinct geographical regions within SC,

# Our Research Project?

## AIMS:

Explore the effect of beliefs and culture on health literacy and self-management of diabetes (SMDM) among AAs from **4 regions in SC**,

To develop a reliable, valid, and generalizable survey tool with items that represent cultural beliefs, spirituality, diabetes experiences, and preference for receiving health information,

# Research Design

- Non-experimental, mixed-method design divided into **3 phases**
- **Phase One/Qualitative:** 14 focus groups to explore illness perceptions, cultural habits and beliefs, trusted information source, style, and preferred format for health information, and inform design of survey,
- **Phase Two/Quantitative: Instrument Development**  
**Cognitive Interviews (CI) (11), Pre-test Instrument to 20 people,**
- **Phase Three/Quantitative:** Administer the survey to 200 individuals (50 from each region),

# Our Approach Community Engagement



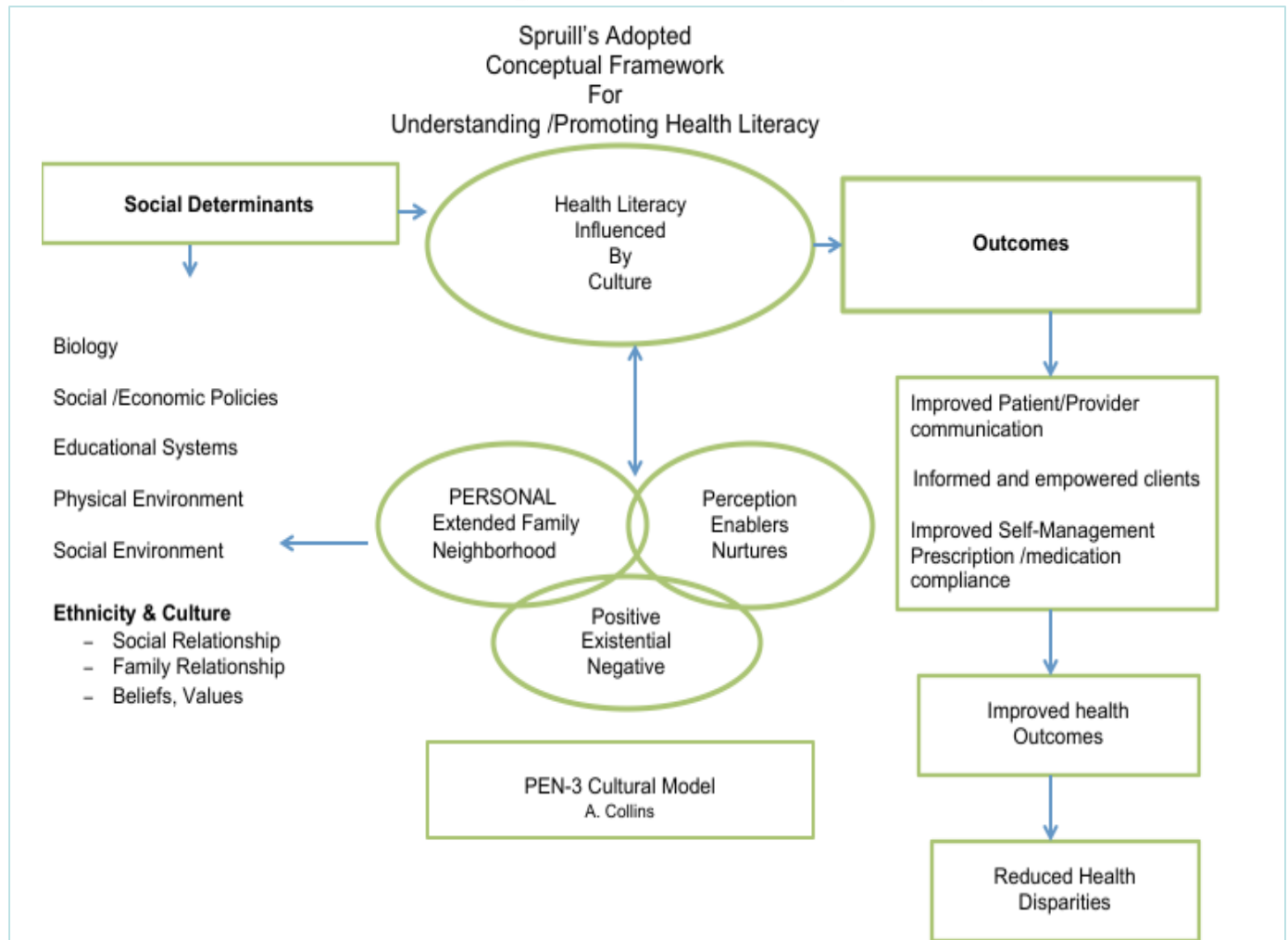
- Most AAs in SC reside in 9 counties known as the Low Country

We propose to study **4 specific areas** in SC known as:

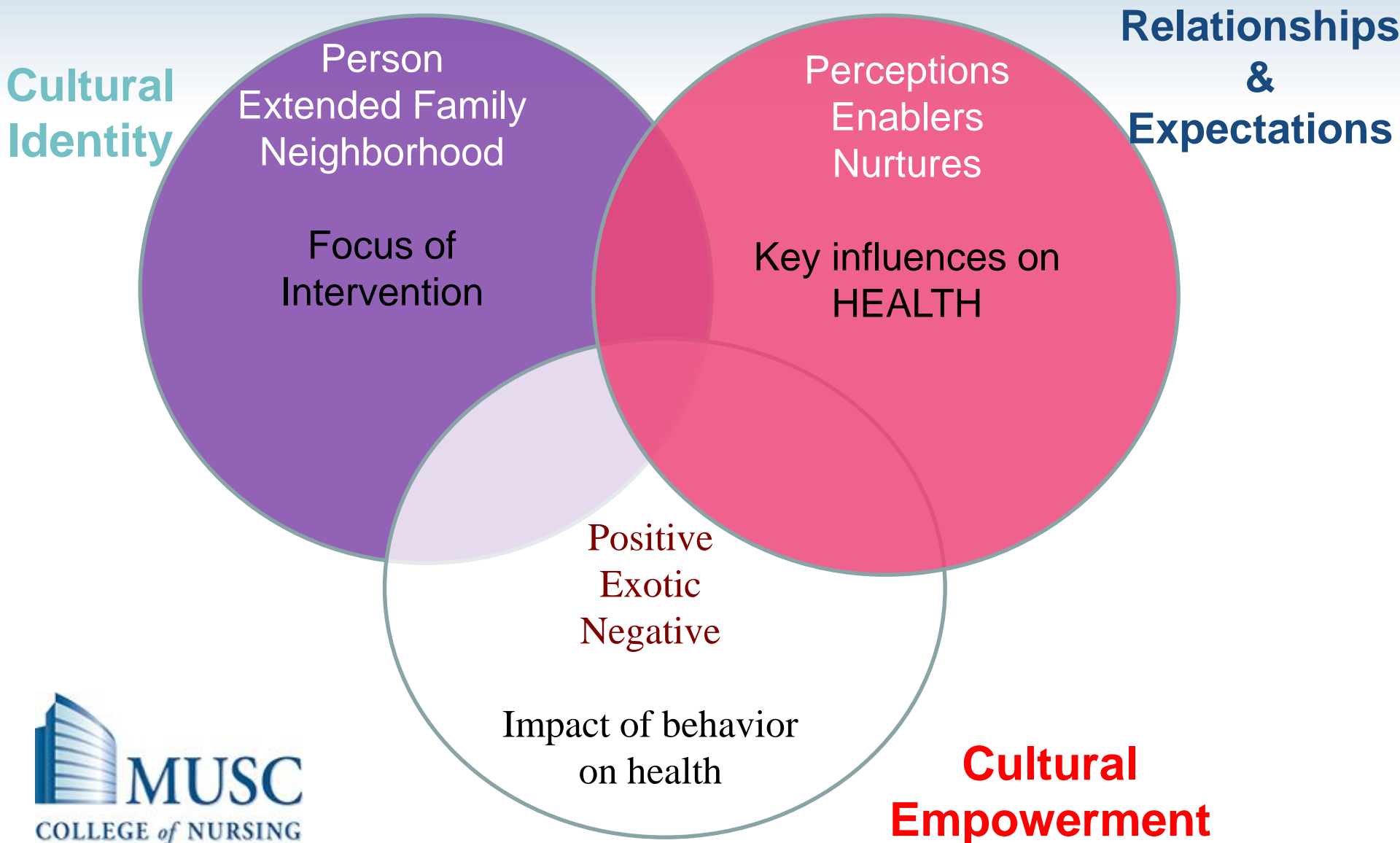
1. Blue Ridge Mountains (BRM)(Greenville, Edgefield)
2. Upper Piedmont Central Midlands/Lower Piedmont, (UP/LP) (Richland, Fairfield)
3. Coastal Plain (Outer, Inner) (OI) (Allendale, Jasper)
4. Pee Dee /Sand hill (SH) (Dillion, Orangeburg)

# Conceptual Framework

- Guided by two models: Airhihenbuwa, PEN-3-Cultural model <sup>12</sup> and the Social Ecological Model (SEM) model.<sup>11</sup>



# PEN-3 Model (Airhihenbuwa, 1995) <sup>12</sup>



# PHASE One/Cultural Identity

The sample included **14 focus groups** with a combined total of **117** participants.

**94% of these were living with diabetes/or had a family history of diabetes**

The focus groups took place from August to November of 2012 at locations that included the following



# Focus Group Demographics

- Gender – **78% Female**, 22% Male
- Age – Mean **Average 54** Years Old
- Less than half 22% Married
- Employed – 25% or had
- Insurance – 26%



# DATA ANALYSIS

## Qualitative Constructivist Grounded Theory Approach

- A **codebook** was developed defining general themes identified in the focus group interview script. Sub-themes emerged from the data analysis and were added to the codebook as they emerged,
- Transcribed textual data from the focus groups were reviewed through a **continuous comparing of data segments**, looking for similarities, differences and themes,

# Results from Focus Group

## “A cry for help”

- The burden of living with diabetes
- Causation
- Location of resources



# Phase Two: Instrument Development

## Title: Development of an Instrument to Measure Diabetes Management, Spirituality, Cultural Beliefs & Health Literacy

### Project DIABETES

#### SURVEY OF FAMILY MEMBER

##### Face to Face Interview

PARTICIPANT # \_\_\_\_\_

Location of Interview:

- ☐ Allendale
- ☐ Edgefield
- ☐ Fairfield
- ☐ Greenville
- ☐ Jasper
- ☐ Dillon
- ☐ Orangeburg
- ☐ Richland

Interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Start Time: \_\_\_\_\_

End Time: \_\_\_\_\_

Gift Card # \_\_\_\_\_

Mode of Interview:

- ☐ In-Person/Face-to-Face    ☐ Phone

### Project DIABETES

#### Survey of People With Diabetes

##### In –Person/Face-to-Face

Participant# \_\_\_\_\_

Location of Interview:

- ☐ Allendale
- ☐ Dillon
- ☐ Edgefield
- ☐ Fairfield
- ☐ Greenville
- ☐ Jasper
- ☐ Orangeburg
- ☐ Richland

Date \_\_\_\_\_

Start Time \_\_\_\_\_

End Time \_\_\_\_\_

Gift Card # \_\_\_\_\_

Interviewer: \_\_\_\_\_

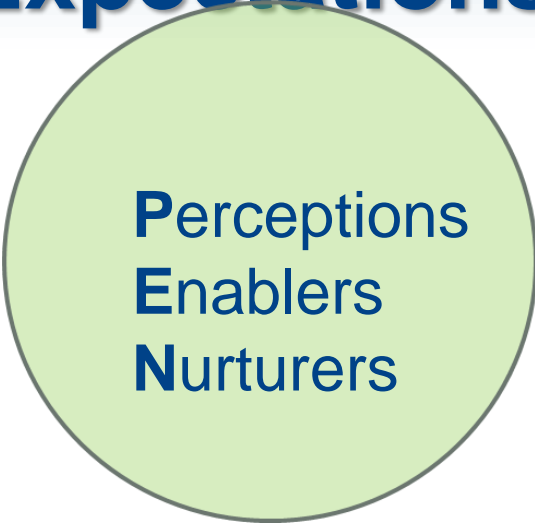
Mode of Interview

- ☐ In-Person/Face-to-Face  
☐ Phone

# Phase Three/Administration of Survey Relationships & Expectations

## Perceptions

- Diabetes is the same as Sugar and Older folks prefer “Sugar”
- Trust doctors the most for Health information
- Fear associated with loss of limbs and eyesight
- Eating small portion is hard
- **Develop a partnership with God to help manage diabetes**
- Need help with medical instructions
- **Hardest part about managing diabetes is eating right, portion control, changing diet ,and reading labels**



Perceptions  
Enablers  
Nurturers

## Enabler

- **Group Sessions/classes or videos with family members** or classes to learn more about Diabetes prevention and management
- Culturally sensitive pamphlets with clear diagrams and words

## Nurturers

- **Want family members to be part of the learning process as well**
- Providers with same culture
- Humility
- **Location of resources**

# Phase Three/Administration of Survey & Results & Cultural Empowerment

## Positive

Learning how to improve diet is most important for what they want to learn

**Willingness to learn**

Positive  
Exotic  
Negative

## Exotic

**At home remedies:**

- Cinnamon
- Tea
- Ginger
- Vinegar & water
- Orange juice

## Negative

- Have fears of amputations, blurred vision/blindness and death
- Want to eat what they want no matter the consequences
- Can't afford medicines, eating healthy, or joining a gym
- No concept of what they need to know or want to know to manage diabetes better
- **Lack of trust in healthcare system**

# Survey Demographics

200 persons completed the surveys

	With Diabetes	Without Diabetes
<b>Mean Age</b>	<b>60 years old</b>	<b>51 years old</b>
Married	35%	35%
<b>Insurance</b>	<b>91% have insurance</b>	<b>78% have insurance</b>
Gender	73% women	81% women
Education	8% college degree 30% HS diploma	18% college degree 23% HS Diploma

# Other Survey Results

## Most Preferred Ways of Receiving Education

- **Group sessions so I can hear about different peoples' situations,**
- **Classes to include family members,**
- Eye-catching, engaging pamphlets/flyers,

## Fears Related to Diabetes

44% percent of the sample acknowledged explicitly that diabetes was a serious condition,

Bringing with it fears of amputation (25%), blindness (21%), and death (17%),

“By not controlling it I mean, you can die from it. That’s something serious,”

# Other Survey Results Cont.

## Perceived Causes

36% believed diabetes is **inherited**,

**38 %** said it is caused by **carbohydrates, sweet foods/drinks**,

## Perceptions about Diabetes

More participants (33%) preferred to call the illness “diabetes” rather than “sugar”

26% voiced that there **was no stigma attached to having diabetes**,

# Dissemination Phase

- **Four Free Community Forums :** Simpson United Methodist Church Allendale County

**Four Stakeholders Meetings**  
Fairfield County : St Luke Baptist Church, Fairfield County



## Project DIABETES receives Award from Congressman Clyburn, 2015



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