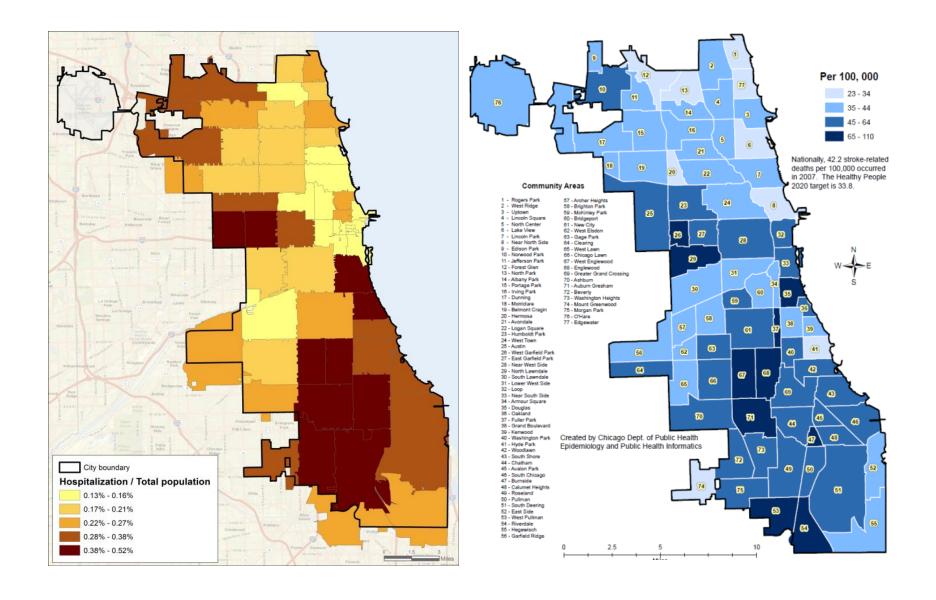
# **CEERIAS**

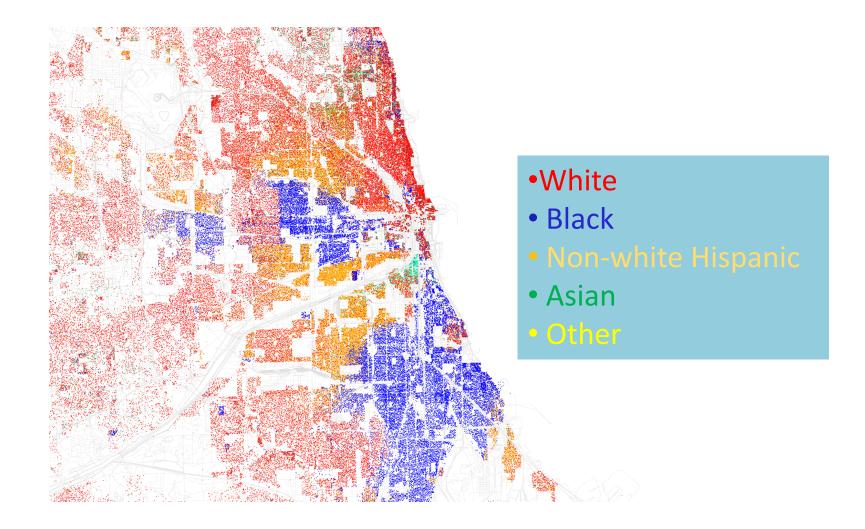
# Community Engagement for Early Recognition and Immediate Action in Stroke

IPHAM PCORI Panel Discussion 1/15/15

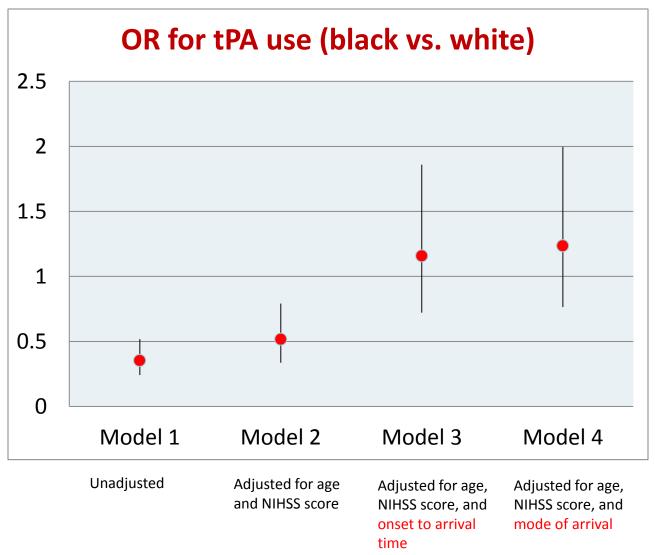
# Background

- Stroke is time-critical disease
- Major cause of disability and death in US
- Disproportionately affects minorities
- Delay in hospital arrival and treatment is major driver of poor outcomes
  - Only 25% arrive within 3 hours of symptom onset
- Race-ethnic disparities exist in stroke awareness, recognition, appropriate action, and acute treatment (i.e., tPA)





# **Preliminary Data**



## **PCORI Themes**

## Assessing Prevention, Diagnosis, and Treatment Options

- Self-care
- Caregiver Support
- Palliative Care

#### Improving Healthcare Systems

- Care transitions
- Telemedicine
- Patient Navigators
- Collaborative Care

#### **Addressing Disparities**

- Cultural/Language Training
- Community Health Workers
- Self-management

#### **Communication & Dissemination Research**

- Shared Decisionmaking
- Parental Support in Pediatric Illness



## **CEERIAS Timeline**

- 2008-2010: Assessment from GWTG data
- 2011: Patient testimonials
- 1/2012: Community Outreach Working Group
- 5/2012-12/2012: Five town halls conducted
- 1/2013: QUESTS-decrease DTN time (increase 911 use)
- 3/2013: Community Advisory Board (mock)
- 5/2013-9/2013: Monthly calls with CAB to define question
- 12/2013: In-person CAB meeting to finalize proposal
- 1/2014: Submitted to PCORI
- 7/2014: Awarded
- 10/2014: Contract started

## **CEERIAS: PCORI Award**

- 325 submissions in the winter cycle
  - 10.2% award rate overall
  - 8.3% of proposals awarded on first submission
  - Only 1 of 6 awarded addressing disparities
- Team effort from start was key

#### **CEERIAS** Research Team

Shyam Prabhakaran (Administrative PI) Neelum Aggarwal (Intervention PI) Knitasha Washington (Community PI)

Peggy Jones Amy Eisenstein Namratha Kandula Christopher Richards Jen Brown Sarah Song Maryann Mason
Soyang Kwon Carlos Corado (Study Coordinator) Heather Beckstrom (Community Coordinator)



#### Partners

Center for Community Health (NU)
Rush University
Chicago Department of Public Health
Chicago Medical Society
Chicago Fire Department
National Association of Health Services Executives
American Heart Association/American Stroke Association
Alliance for Research in Chicagoland Communities
Center for Faith and Community Health Transformation
Stroke Survivors Empowering Each Other
Coalition of Limited English Speaking Elderly
Chicago Hispanic Health Coalition
A Safe Haven
Mount Sinai Hospital
Holy Cross Hospital

Advocate Trinity Hospital

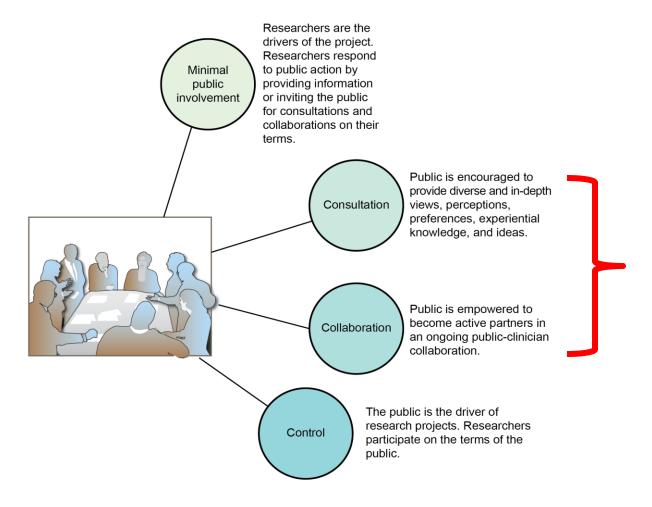
#### Community Advisory Board

Lisa Bartlett Tom Behrens
Marta Pereyra Kimberly Rogers
Kathleen O'Neill Amanda Kelley
Esther Sciammarella Kirsten Peachey

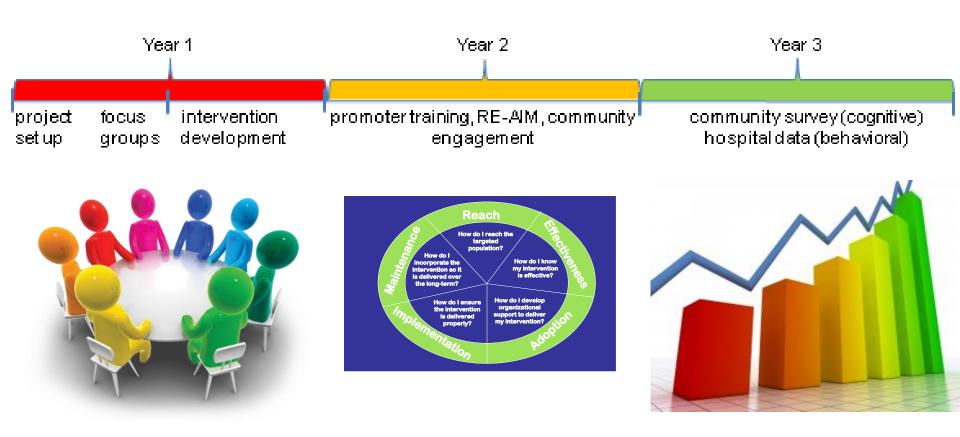
#### **Consultants**

Ronald Ackermann
Zeeshan Butt

# Types of Engagement



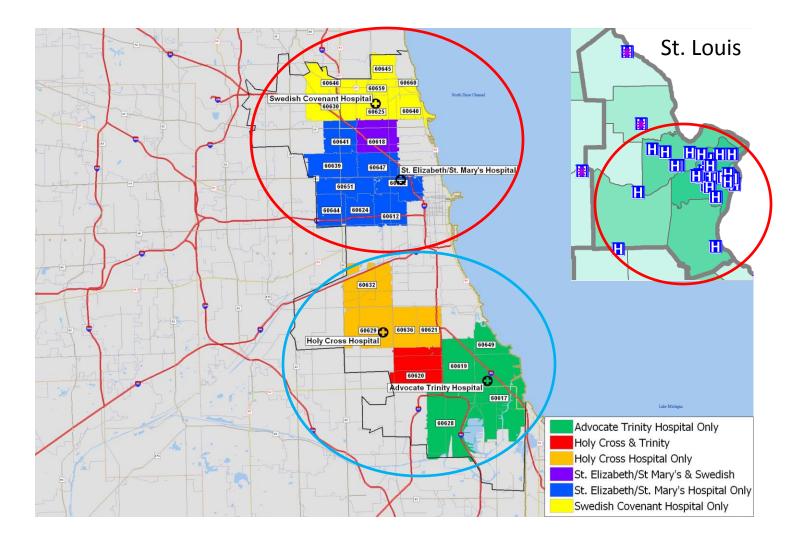
# Approach



## **Aims**

- 1) To examine personal, community, and cultural barriers to calling 911 after stroke onset and adapt a culturally-tailored intervention for delivery surrounding 2 hospitals on the south side of Chicago
- 2) To implement a culturally-adapted stroke awareness and action program and monitor its penetration and adoption using the RE-AIM framework in the south side of Chicago
- 3) To assess change in early hospital arrival and EMS use at 2 intervention hospitals before and after the community intervention.

# Comparative Effectiveness



## Patient-centeredness

#### Pre-submission

- Identified a topic that patients and families have emphasized as important to them (stroke related disability and disparities in acute stroke)
- Ensured primary outcome resonated (EMS use and early arrival)
- Helped select community in Chicago to target (South Side)

### Since awarded (planned)

- Glean patient, caregiver, lay community member views, perceptions, and ideas (Aim 1)
- Adapt and refine planned intervention based on community input and cultural needs (Aim 1)
- Deliver intervention by means that are trustworthy and effective based on community input (Aim 2)
- Disseminate results

# Patient/community engagement

- Multiple stakeholders (CAB, organizations) took part in shaping the research question and reviewing proposal over 1 year (2013)
- Shared governance since beginning
  - CAB has reviewed and modified all key pieces of the project thus far
  - Community PI and Community Coordinator
  - Patients/stakeholders represent 11 of 19 members of CAB and research teams
- Partnership building and reciprocal engagement
  - Giving back in form of on-site presence, materials, talks
  - Social media to ensure real-time engagement and dissemination

## **Community Engagement**



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