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)
Community Engagement for Early Recognition and Immediate Action in Stroke (CEERIAS) Study
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- White
- Black
- Non-white Hispanic
- Asian
- Other
Preliminary Data

OR for tPA use (black vs. white)

Model 1: Unadjusted
Model 2: Adjusted for age and NIHSS score
Model 3: Adjusted for age, NIHSS score, and onset to arrival time
Model 4: Adjusted for age, NIHSS score, and mode of arrival

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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 Decision-making
- 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
Types of Engagement

- **Minimal public involvement**: Researchers are the drivers of the project. Researchers respond to public action by providing information or inviting the public for consultations and collaborations on their terms.

- **Consultation**: Public is encouraged to provide diverse and in-depth views, perceptions, preferences, experiential knowledge, and ideas.

- **Collaboration**: Public is empowered to become active partners in an ongoing public-clinician collaboration.

- **Control**: The public is the driver of research projects. Researchers participate on the terms of the public.

Community Engagement for Early Recognition and Immediate Action in Stroke (CEERIAS) Study
Approach

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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.

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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
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