

Development, Implementation, and Early Successes of a Community Research Infrastructure to Facilitate Ethical Engagement of Minorities

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Presenter Disclosures

Kate Stewart

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months: No relationships to disclose

Background on Issue

- Limited minority research participation impedes achievement of racial health equity
- Causes are complex:
 - lack of trust
 - power differences
 - participant burden
 - access to healthcare and research opportunities
 - relevance to minority concerns

Background on Issue

- Intentional structural supports addressing ethical engagement:
 - strong community partnerships
 - shared financial resources
 - community-based participatory research (CBPR) approaches
 - community advisory boards (CABs)
 - community health workers

Community Linked Research Infrastructure (CLRI)

- CBPR project focused on ethical engagement of minorities in research as both partners and participants
- Incorporated intentional structural supports
- Initiated in 2010 through community academic partnership with 3 year NIH grant

CLRI Program – Overview of Structural Supports

- Strong community partnerships
 - Long-term academic/community partnership building on successful program model
- Shared financial resources
 - Joint grant funding
- Community-Based Participatory Research
 - Community partnered in design, implementation, and evaluation
- Community Advisory Boards (CABs)
 - Role of CLRI CAB
- Community Health Workers
 - Community Connectors as key component of CLRI

History of Community Academic Partnership

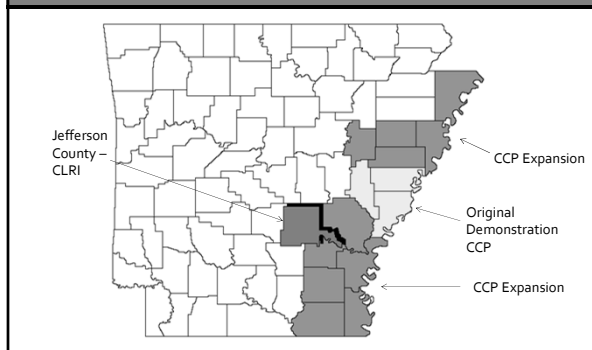
- Tri County Rural Health Network hires community health workers called Community Connectors
 - Connectors are lay persons from the community trained to
 - identify Medicaid-eligible elderly adults and those with disabilities who need long term care and
 - connect them to home and community-based services
- College of Public Health
 - assisted in obtaining grant funding for demonstration
 - conducted cost impact analysis showed Medicaid savings
- Medicaid funded Community Connector Program (CCP) expansion to 15 counties
- COPH/Tri County partnered to adapt CCP for CLRI

Ethical Engagement – Addressing Relevance and Power Differences

Community Engagement in all phases

- Partners: College of Public Health, Tri County, and faith community
 - Grassroots and practice-based community engagement
 - Academic expertise: in behavioral, policy, and evaluation research
- Deliberative Democracy Forums informed focus on chronic disease and access to research opportunities
- Tri County partnered in proposal development, received almost 45% of grant funds
- Weekly meetings of diverse, interdisciplinary team

Arkansas Delta Region



Ethical Engagement – Addressing Participant Burden and Access

- Community Engagement in Formative phase
 - CITI and CBPR training for partners and connectors
 - Team and CAB involvement in health survey design
 - Feedback to CAB re: connectors' experience, survey results



Ethical Engagement – Increasing Access to Services and Research

- Connectors:
 - identify resources (relationships/directory)
 - make contacts for program and document
 - needs, interests
 - health status, service experience
 - willingness to be contacted about services and research opportunities
 - connect program enrollees to resources
 - enter data in health registry
 - share information about research opportunities
 - attempt to recruit researchers with relevant expertise

Health Registry

- Information on program enrollees
- Data facilitates connecting
- Collected for service purposes
- Identifiable data controlled by Tri County
- Data sharing agreement for other uses:
 - data request form for other investigators
 - pre-proposal queries
 - limited datasets for analysis (requires IRB approval)

Enrollment and Demographics

- Approximately 3700 enrolled in health registry to date
- Registry questionnaire data available for 653 as of May 2013
- Demographics:
 - 78%: African American
 - 70%: Female
 - 47 years: Mean Age

Willingness to Be Contacted

- Willingness to be contacted about:
- services that may be of interest to you?
 - 96% of African Americans
 - 98% of whites
 - research opportunities that may be of interest to you?
 - 90% of African Americans
 - 91% of whites

Ethical Engagement – Enhancing Trust

- Sustainability and long-term commitment
 - Informing researchers of infrastructure
 - Evaluating sample characteristics for potential research
 - Researchers including infrastructure in new grants
 - Translational research institute providing interim support

New Projects and Partnerships

- Grants incorporating CLRI into budgets:
- 10+ new researchers engaged with community
 - 2 new projects funded (total \$1.6m)
 - 5 projects submitted (\$12.5m requested)
 - 2 new projects to submit (\$2.85m)

Members of Research Team



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CLRI Connectors



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