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**

- Jefferson County – CLRI
- CCP Expansion
- Original Demonstration
- CCP
- CCP Expansion

**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
- Kate Stewart
- Holly Felix
- Mary Olson
- Naomi Cottoms
- Johnny Smith
- Ashley Bachelder
- Tanesha Ford
- Leah Dawson
- Paul Greene

### CLRI Connectors
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<td>- Community Connectors</td>
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