Charles R. Drew University Community Faculty, Healthy African American Families, RAND, & UCLA/CTSI partnered to develop this presentation.
What is Community-Partnered Participatory Research (CPPR)?

Bowen Chung, MD, Co-Leader
Felica Jones, Director of Programs, Healthy African American Families
Objectives

1. Rationale for CPPR

2. What is CPPR?

3. Examples of CPPR projects
   - Community Partners in Care (CPIC)
   - Center for Excellence in Assisted Living (CEAL)

4. Questions
Health Disparities

- Racial and ethnic disparities
  - Healthcare: Access, Quality
  - Health: Morbidity and Mortality

Minority Research Participation

- Racial and ethnic minorities have lower participation rates in all forms of biomedical research
  - Clinical Trials
  - Genetics Research

Talmadge, 2002; Wendler, Kington, Madans, Van Wye, Christ-Schmidt, Pratt, Brawley, Gross, & Emanuel. (2005)
Minority Research Participation

- Limited access to research
  - Not knowing about research opportunities
  - Research opportunities not being convenient
  - Not understanding research

- Distrust of government programs and health services

- Lack of trust due to tragic historical legacy of research abuses of minority populations
  - Tuskegee and Guatemalan Syphilis Studies
  - Antebellum research abuses

Institute of Medicine, 2011; Jones, 1993; Gamble, 1997; Corbie-Smith & Ford, 2006; Corbie-Smith & Thomas, 2002.
Participatory research approaches are recommended:

- to engage participants and
- to enhance trust in research and services
Principles of Community Engagement

Before Community Engagement...

- Be clear about purposes or goals and the populations and/or communities you want to engage.

- Become knowledgeable about the community (culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experience with efforts by outside groups to engage it in various programs) and its perceptions of those initiating the engagement activities.
Principles of Community Engagement

Before Community Engagement...

- Know where you want to go.

- There are multiple levels of community engagement from community participation in a pre-designed study to community advisory board to using community sites to having community as a full partner.

- Be clear what is most appropriate for your project and be clear and transparent with your potential community partners.
Community Based Participatory Research (CBPR)

Originally an approach to engaging low income minority communities around research

“an approach to research meant to enhance the value of studies for both researchers and the community being served.” (AHRQ)

“a collaborative research approach that is designed to ensure and establish structures for participation by communities ... in all aspects of the research process
Principles of Community Engagement

For CBPR, it is necessary to...

- Go to the community, establish relationships, build trust, work with the formal and informal leadership, and seek commitment from community organizations and leaders to create processes for mobilizing the community.

- Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.
Principles of Community Engagement
For CBPR to Succeed...

- Partnering with the community is most likely to create lasting change and improve health.

- Recognize and respect the diversity of the community in planning, designing, and implementing approaches to engaging a community.

- Community engagement can best be sustained by identifying and mobilizing community assets and strengths and by developing the community’s capacity and resources to make decisions and take action.

- Be prepared to release control of actions or interventions to the community and be flexible enough to meet its changing needs.

- Community collaboration requires long-term commitment by the engaging organization and its partners.
Healthy African American Families (HAAF)

- **Goal:** To provide a forum for community to take active leadership in improving its own health

- **Community Participatory Partnership Research Model (CPPR)**
  - Community Engagement Approach
  - Applied the Model to many health problems
  - Depression offered an opportunity to partner with evidence-based research approaches

Slides courtesy of Loretta Jones, Healthy African American Families II
CPPR

CPPR is essentially CBPR but intentionally highlights “partnership” in its name to differentiate itself from approaches that have positioned themselves under the CBPR umbrella by establishing a community base for their project without truly embracing authentic partnership, thereby diluting the true meaning of CBPR.
CPPR
Developed by listening to the community
## Research Process

<table>
<thead>
<tr>
<th>Traditional Research Approach</th>
<th>Community-engaged Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher defines problem</td>
<td>Community identifies problem or works with researcher to identify problem</td>
</tr>
<tr>
<td>Research IN or ON community</td>
<td>Research WITH community as full partner</td>
</tr>
<tr>
<td>People as subjects</td>
<td>People as participants and collaborators</td>
</tr>
<tr>
<td>Researchers gain skills and knowledge</td>
<td>Researchers and community build community capacity</td>
</tr>
<tr>
<td>Researchers control process, resources, data</td>
<td>Researchers and community share control equally</td>
</tr>
<tr>
<td>Researchers own data, control use and dissemination</td>
<td>Data are shared: Researchers and community decide its use and dissemination</td>
</tr>
</tbody>
</table>

Adapted from Mary Ann McDonald, Duke University by Loretta Jones, Healthy African American Families II
## Find The Win-win To Engage

<table>
<thead>
<tr>
<th>Sector</th>
<th>Wins</th>
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<tbody>
<tr>
<td>Community</td>
<td>Better daily lives</td>
</tr>
<tr>
<td>Community Based Organizations</td>
<td>Recognition, financial support, networking, training, resources</td>
</tr>
<tr>
<td>Business Community</td>
<td>Increased market share, image, tax write-off, visibility</td>
</tr>
<tr>
<td>Government</td>
<td>Community support; public trust in evaluation</td>
</tr>
<tr>
<td>Universities</td>
<td>Greater impact, partners for research, 2-way knowledge transfer promotes innovation or improves recruitment</td>
</tr>
</tbody>
</table>
Getting Engaged

- Develop Equitable Partnerships
  - Share power, listen, respect differences
  - Develop and honor written agreements
  - Structure activities to level the playing field

- Embrace Community
  - Not as "subject" but partner
  - Honor community strengths while building capacity
  - Share and learn across community and academic partners in two-way exchange
  - Align funding and resources to fit principles and support win-win
Community Partners In Care
PI Kenneth Wells
Co-PI Loretta Jones & Elizabeth Dixon
What Is Community Partners In Care?

- A community – academic partnership
- A NIMH funded, randomized trial
- Depression care quality improvement, training and capacity development program
What is Community Partners in Care?

- 2 Communities: Hollywood/Metro & South LA
- 93 programs in 50 agencies
- Programs randomized to technical assistance (Resources for Services) or Community Engagement and Planning
- Depressed clients who enrolled followed for 1 year
Population Served By Agencies (N=4436)

- Mean age 46.5
- 54 % female
- 28 % married
- 39 % < high school
- 23 % working at all
- 40 % no insurance
- 65 % family income from work <$10K

- Race/ethnicity:
  - 45 % Latino
  - 40 % African Am.
  - 15 % white/other
Working together in an *equal* partnership

To learn how to improve depression care

And build community strength
How can we beat depression in our community?

- Community Capacity
- Partnered Planning (Vision)
- Partnered Trial (Valley)
- Partnered Dissemination (Victory)
- Resources for Services (Agency support)
- Community Engagement & Planning (Network support)
- Outcomes

PI Wells, Co-PI Jones and Dixon, CPIC
Resources for Services

Community Engagement & Planning
Community Partners In Care: Outcomes

- Agencies
  - Participation rates in trainings: % of agencies, % of providers in agencies
  - Depression services over 1 year

- Providers
  - Participation rates in trainings: # of staff, # of hours
  - Depression services and staff skills and knowledge over 1 year

- Clients at 6 and 12 months
  - Depression
  - Functioning
  - Employment/housing
  - Quality of life
Core Training For CEP Group

Participants: 264
Hollywood: 121
South L.A.: 143

➢ Trainings and webinars, 3/19/10-1/31/11, 32 days
➢ CBT sub-study (Dr. Vicky Ngo)

Webinars/site Visits for RS Group

Participants: 49
SPA 4: 25, SPA 6: 24
02/21/10-12/29/10, 32 days
309 Received Specific Skills Training in 50 CPIC Agencies

Other: med management, grant writing, self care, active listening, leadership
Optimal Physical Health

YES to ALL:

- health limits moderate activities during a typical day (not at all)
- health limits climbing stairs during a typical day (not at all)
- accomplished less due to physical health past 4 weeks (no)
- limited work or other activities due to physical health past 4 weeks (no)
- physically active in past 6 months: quite active

PI Wells, Co-PI Jones and Dixon, CPIC
Wellness

YES to at least 1 item

- felt calm and peaceful past 4 weeks
- had a lot of energy past 4 weeks
- been a happy person past 4 weeks

**Diagram:**
- RS: 34%
- CEP: 46%
- p = 0.02
Poor Mental Health

YES to ALL:
- Depression, PHQ8 score >=10
- MHI506<56
- MCS1206<40

38%

p=.04

Poor mental health

RS  
CEP
Homeless Risk Factors in Past 6 Months

- Homeless/no place to say: 23% (RS) vs 18% (CEP)
- Evicted/house foreclosed: 8% (RS) vs 7% (CEP)
- Major financial problem: 45% (RS) vs 40% (CEP)
- Worried about the food: 48% (RS) vs 40% (CEP)
Community Partners In Care: Community Capacity Building

Provider training

- 2-way leadership development
- CME/CEUs, certificates of appreciation for community
- Letters of support for community grants
- Research opportunities
- Data for policy makers
- Sustainable intervention website
  - National Library of Medicine grant
- Common Hope: Improve lives, inform policy debates
Suggested Articles


• “Chapter 1: Community-Based Participatory Research,” A Manual for Community-Based Participatory Research, Collaborative Studies of Long Term Care – University of North Carolina at Chapel Hill and Center for Excellence in Assisted Living” (CEAL-UNC Collaborative): 2nd edition – National CTSA Consortium

Suggested Reading


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Questions?

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