Community-Engaged Research Elements & PCORI

Sarah Gehlert, PhD

E. Desmond Lee Professor of Racial & Ethnic Diversity
The George Warren Brown School of Social Work
Professor, School of Medicine
Chair, Center for Community Engaged Research
Institute of Clinical & Translational Sciences
Washington University in St. Louis
• PCORI seeks meaningful involvement of patients & other stakeholders in all the steps of research
• A Patient & Stakeholder Engagement Plan that outlines early & continuous engagement distinguishes PCORI from most other funding agencies

PCORI & Community Engagement
1. Expand bidirectional communication with St. Louis communities to strengthen ICTS research
2. Provide ongoing education on the scientific & ethical principles of community-engaged research
3. Strengthen & expand collaborative research partnerships between ICTS investigators & community stakeholders

Center for Community Engaged Research
### Deaths /100,000 Population

<table>
<thead>
<tr>
<th>ZIP Code</th>
<th>Overall Mortality</th>
<th>Map Quartile</th>
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</thead>
<tbody>
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</tr>
<tr>
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<td>63101**</td>
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</tr>
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<tr>
<td>63109</td>
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<tr>
<td>63102**</td>
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</tr>
<tr>
<td>63103</td>
<td>665.1</td>
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</table>

**STL City**
- 966.6

**STL Black**
- 1111.5

**STL White**
- 873.5

**MO**
- 866.6

**MO Black**
- 1028.2

**MO White**
- 854.3

**US**
- 768.4

**US Black**
- 970.0

**US White**
- 756.9

**Small population - interpret with caution**

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Source: The City of St. Louis Department of Health, 2013
Categories of Community-Academic Research

- Community-Placed Research
- Community-Based Research
- Community-Engaged Research

Degree of community participation
Process of inclusive participation in research in which academic researchers & community stakeholders act in concert to create a productive working & learning environment that extends from before a research project begins to after its completion.

NIH Director’s Council of Public Representatives

Definition of Community-Engaged Research
• Better understanding of what is determining health problems
• Increased community participation in research (e.g., increased trust, increased enrollment in research studies)
• Increased sustainability of change
• Increased success of public health practices, programs, & policies

Advantages of Community Engagement
Collaborative approach to research that equitably involves all partners in the research process & recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge & action for social change to improve community health & eliminate health disparities.

WK Kellogg Community Scholar’s Program (2001)

Definition of Community-Based Participatory Research*

*CBPR; see Community Engagement Plan C for a PCORI example
Relies on “trust, cooperation, dialogue, community capacity building, & collaborative inquiry toward its goal of improving health and well-being”

Winkler & Wallerstein, 2003

Community-Based Participatory Research
Is not a research method itself, or a theory, but an orientation to research

It can be:

- qualitative
- quantitative
- mixed methods
- randomized clinical trial
- other

Community-Based Participatory Research
# Research Process Through Two Lenses: The Best of Both Worlds

<table>
<thead>
<tr>
<th>Step</th>
<th>Community Perspective</th>
<th>Research Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formulating questions &amp; hypotheses</td>
<td>Matches life experiences of community members</td>
<td>Testable by science</td>
</tr>
<tr>
<td>Obtaining background information</td>
<td>Community voices; experiential knowledge</td>
<td>Professional literature</td>
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<tr>
<td>Methods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• sample</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• measures</td>
<td>• those who know</td>
<td>• objectively obtained to achieve statistical power</td>
</tr>
<tr>
<td>• data collection</td>
<td>• meaningful to community</td>
<td>• psychometrically sound</td>
</tr>
<tr>
<td>• analysis</td>
<td>• culturally appropriate</td>
<td>• scientifically rigorous</td>
</tr>
<tr>
<td>• culturally appropriate</td>
<td></td>
<td>• using statistical methods</td>
</tr>
<tr>
<td>Evaluating results</td>
<td>Clinically significant</td>
<td>Statistically significant</td>
</tr>
<tr>
<td>Drawing conclusions</td>
<td>Relate to life experiences</td>
<td>Relate to original hypotheses</td>
</tr>
<tr>
<td>Disseminating results</td>
<td>Lay media; community presentations</td>
<td>Scientific journals</td>
</tr>
</tbody>
</table>
Establishing Community & Academic Partnerships

Methods
The ideal is for projects to originate in communities,* yet many projects would not occur without the initiative of academic researchers.

It is important that:

• Projects are high on the agendas of communities
• Researchers have the skills & knowledge to ensure that partnerships are balanced & fair so that changes are sustainable

Who Initiates Partnerships?

* See Nueva Vida sample engagement plan for an example (Engagement Plan D)
Community & Academic Partnerships Across Research Projects
Communities are not homogenous
Not completely defined by shared geography (e.g. virtual communities of persons with rare genetic disorders or rare cancers)
All members may not be “of the same mind”
Communities occur at many levels, e.g., health departments or FQHCs*

*FQHC=federally-qualified health centers

Defining the Community
Possible Steps to Engaging Communities

Determine research questions

Define community appropriate to the question or goal

Explore existing partnerships  Create new partnerships

Focus groups  Town hall meetings
Mechanisms of Community Engagement

Focus groups
Community-advisory boards

Collaborations/Coalitions/Partnerships
Focus Groups

Research discussion groups conducted by a facilitator or facilitators & designed to create a free-flowing exchange/conversation about one or more issues related to a general topic.

Usually 10-12 persons.
Groups of community stakeholders representing key constituencies that meet regularly to provide community perspectives, help set research agendas, review research, & advise on issues that arise throughout the research process.

Community Advisory Boards
• Usually 9-15 persons
• Should be those who will evaluate the process & issues fairly & critically
• Must meet regularly face-to-face
• Need a system of achieving rapid feedback at other times
• Should be compensated for time
• Should represent the stakeholders of focus re: age, gender, religion, SES

Community Advisory Boards
Coalitions/Collaborations/ Partnerships

- Longer-term entities
- May span research projects
- Heighten sustainability
- Increase odds of policy change
- Take time to develop

Metropolitan Chicago Breast Cancer Coalition

Illinois Reducing Breast Cancer Disparity Act (PL95-1045)