Presentation Overview

By the end of this presentation, you will be able to:

1. Describe what community engagement is and why it is important in research
2. Understand the continuum of community engagement
3. Name at least two strategies to initiate and/or maintain community engagement in research
Consider for a moment the following questions...

Why is your research important for a specific patient or other population?

What do you think could be gained if people in that population knew more about your research?
“When health and health care [research,] policies and programs designed to improve outcomes are not driven by community interests, concerns, assets, and needs, these efforts remain disconnected from the people they intend to serve.”

(NAM 2022, p.1)

What is Community Engagement in Research?

• Research that involves individuals, groups, and/or organizations from one or more communities.
• Communities can be geographic, ethnic/racial, or other.
• No standard approach; engagement is a continuum.
• May be achieved during a time-limited project, but it’s best when evolves into longer-term partnerships that move from the traditional focus on a single research or other project.
# Continuum of Community Engagement in Research

## Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

<table>
<thead>
<tr>
<th>Outreach</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Shared Leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Some Community Involvement</strong>&lt;br&gt;Communication flows from one to the other, to inform&lt;br&gt;Provides community with information.&lt;br&gt;Entities coexist.&lt;br&gt;Outcomes: Optimally, establishes communication channels and channels for outreach.</td>
<td><strong>More Community Involvement</strong>&lt;br&gt;Communication flows to the community and then back, answer seeking&lt;br&gt;Gets information or feedback from the community.&lt;br&gt;Entities share information.&lt;br&gt;Outcomes: Develops connections.</td>
<td><strong>Better Community Involvement</strong>&lt;br&gt;Communication flows both ways, participatory form of communication&lt;br&gt;Involves more participation with community on issues.&lt;br&gt;Entities cooperate with each other.&lt;br&gt;Outcomes: Visibility of partnership established with increased cooperation.</td>
<td><strong>Community Involvement</strong>&lt;br&gt;Communication flow is bidirectional&lt;br&gt;Forms partnerships with community on each aspect of project from development to solution.&lt;br&gt;Entities form bidirectional communication channels.&lt;br&gt;Outcomes: Partnership building, trust building.</td>
<td><strong>Strong Bidirectional Relationship</strong>&lt;br&gt;Final decision making is at community level.&lt;br&gt;Entities have formed strong partnership structures.&lt;br&gt;Outcomes: Broader health outcomes affecting broader community, Strong bidirectional trust built.</td>
</tr>
</tbody>
</table>

Reference: Modified by the authors from the International Association for Public Participation.

[https://www.atdsr.cdc.gov/communityengagement/](https://www.atdsr.cdc.gov/communityengagement/)
Continuum of Community Engagement in Research

Limited interactions
Often not focused on specific research studies

Examples:
• Presentation of research findings to community
• Presentation of community needs to researchers
Continuum of Community Engagement in Research

Interactions on limited aspects of study

Example:
- Community experts as research advisors
- Might involve funding to community expert
Continuum of Community Engagement in Research

Interactions that might involve study development, implementation and/or outcomes and implications

Example:

• Community advisory board for research study
• Usually involves funding to support CAB members
Interactions that **usually** involve study development, implementation and/or outcomes and implications

**Examples:**
- Community members as part of the core research team
- Community subcontracts to implement aspects of the study design
Continuum of Community Engagement in Research

Interactions that start with development of research question, collaborative design and methods, and joint analyses and dissemination

Examples:

• Community as MPIs or CoIs
• Community-based participatory research
• Shared decision making throughout study
What are the benefits of research participation for community members and academics?

1. Access to information and resources
2. Opportunities for networking
3. Learning
4. Improved relationships among stakeholders
5. Increased capacity for problem solving
6. Contact with hard-to-reach ("hardly reached") populations
7. Personal recognition
8. Helping to solve long-term community problems
What are the potential costs of research participation for community members and academics

1. The time and energy required to build relationships
2. Infrastructure to sustain relationships
3. Potential lessening of control (mainly for academics) over study
Let’s say you want community engagement in your study. Now what?

First, get on the same page with the research team about what it means to engage with the community.
Get to know the community and its constituents

Next, start your community engagement effort.

Establish strategies to initiate relationships and guide interactions

Build formal and informal networks to maintain relationships
Get to know the community and its constituents

**Tips:**

- Identify existing informal (e.g., churches) or formal networks (e.g., coalitions)
- Ask to present on your research (e.g., to students, or to community leaders)
- Focus on the “whys” and “whats”
- Avoid focusing on the detailed “hows”
- Ensure terminology is targeted to lay audience
Tips:

- Invite community members and/or leaders to learn more (e.g., tour lab, meet students, etc)
- Offer ongoing opportunities to interact with researchers (e.g., regular meetings in community)
- “Do not show up empty handed” (e.g., provide lunch, honoraria, etc)

Establish strategies to initiate relationships and guide interactions
Build formal and informal networks to maintain relationships

Tips:

- Take notes of community responses and recommendations
- At subsequent opportunity, report back on how community input was considered by academics
- Ask questions to facilitate further interactions
- Include community members as coauthors on conference presentations and/or papers
1. Identify and characterize the cancer burden in Orange County

2. Partner with community leaders and organizations to develop, implement and evaluate outreach education and policy advocacy campaigns

3. *Catalyze community-engaged research across CFCCC’s programs and members*
Office of Community Outreach & Engagement

Orange County Cancer Coalition (OC3)

Community Equity Board

Director, COE

Navigator

CHE

Navigator

CHE

### COE Strategic Plan - Goals

<table>
<thead>
<tr>
<th>Goal</th>
<th>NCI Merit Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Assess and prioritize catchment area cancer prevention,</td>
<td>1, 2</td>
</tr>
<tr>
<td>detection, survivorship and research needs</td>
<td></td>
</tr>
<tr>
<td>2. Increase communication and collaboration between community and</td>
<td>3, 4</td>
</tr>
<tr>
<td>researchers</td>
<td></td>
</tr>
<tr>
<td>3. Increase accruals of women and minorities into clinical trials</td>
<td>5</td>
</tr>
<tr>
<td>4. Increase cancer outreach, education, and advocacy to reduce the</td>
<td>6</td>
</tr>
<tr>
<td>cancer burden in the catchment area</td>
<td></td>
</tr>
<tr>
<td>5. Extend reach of COE in and beyond catchment area</td>
<td>8</td>
</tr>
<tr>
<td>6. Collaborate on education and mentoring with CRTEC to address</td>
<td>New</td>
</tr>
<tr>
<td>catchment area needs</td>
<td></td>
</tr>
</tbody>
</table>

# trainings about research and community engagement
Community engaged normal breast tissue collection project
What would be most helpful to know to incorporate community engagement into your research?

Thank you!
Sora Park Tanjasiri
tanjasir@uci.edu