Strengthening Research Capacity through Community Engagement

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Community Engagement in Research

- Ultimate goal of translational research - to improve human health
- Requires meaningful community engagement across the entire spectrum of research from basic science to community and population health research.

**What is Community Engagement?**

…the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people.

<table>
<thead>
<tr>
<th>Increasing Level of Community Involvement, Impact, Trust, and Communication Flow</th>
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<tbody>
<tr>
<td><strong>Outreach</strong></td>
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<tr>
<td>Some Community Involvement</td>
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<tr>
<td>Communication flows from one to the other, to inform</td>
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<tr>
<td>Provides community with information.</td>
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<tr>
<td>Entities coexist.</td>
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Reference: Modified by the authors from the International Association for Public Participation.

Figure 1.1. Community Engagement Continuum. *Principles of Community Engagement, 2nd Edition.*
The Community Engagement Studio (CES) is a structured guidance session that engages patients, consumers, and other non-academic stakeholders in biomedical and clinical research.

Stakeholders serve as experts, providing feedback based on first-hand experience and knowledge of the community.
Why is the CES Innovative?

- Responsibility to recruit community members for feedback does not solely rely on the researcher
- Guided approach for both the community and researchers (coaching)
- Systematic methodology to engage community members in different stages of research and reduce barriers to participation in research
Evolution of CES

- CTSA Translation Studio Model
- Input from MVCERC Community Advisory Council and community partners
- Partnership with UNC Chapel Hill to develop and test new models for community engagement.
- PCORI grant to study impact of CES on research.
CES Team

**Community Expert**: Stakeholder (consumer, patient, caregiver, provider) with first-hand experience

**Community Navigator**: manages the logistics of the CES, recruits and orients experts, builds academic-community partnerships, prepares researcher.

**Faculty**: expertise in CEnR, CER, PCOR; coaches researcher.

**Facilitator**: Neutral person skilled in moderating group process.
Request for CES

CES team reviews requests

Consultation with CES team

Determines stakeholders' characteristics

Recruited "experts"

Coaching on engaging non-researchers

Pre-meeting training

Facilitated Meeting
- Researcher presentation
- Stakeholder feedback
- Co-learning experience

Researcher Outcomes
- changes in knowledge, attitudes, study design
- more patient-centered interventions, comparators, and outcomes
- usefulness of evidence for decision-making

Stakeholder Outcomes
- perceptions of value, relevance and acceptability
- changes in knowledge and attitudes about research
- relevance of outcomes to patients

Summary of oral and written stakeholder feedback
Benefits for Researchers

- Access to community stakeholders simplified
- Immediate feedback at various stages of the research process
- Opportunity to build a relationship with community partners
- Deepen understanding of community
- Feedback on feasibility
- Background in community-engaged research not required
Benefits for the Community

- Assurance that community **voice** is present
- **Opportunity** to be active participants and engage in how and what types of research is conducted
- Sense of ownership and/or satisfaction for providing input; their opinion matters
- Sense of accomplishment when changes are made to research due in part to their input
Focus of Past CE Studios

- Research design
- Recruitment/retention
- Dissemination
- Partnership building
- Implementation
- Ethics
- Consent
- Research question
Outcomes of CES

- Intervention redesigned
- Study design changed
- Consent document modified
- Recruitment materials revised
- Participant incentives added/modified
- Revised proposal submitted
Focus of Prior CE Studios

- Neurology
- Pulmonary and Critical Care
- Cancer Epidemiology
- Bioinformatics
- Human Genomics
- Cardiology
- Obstetrics
- Cancer Biology
- Clinical Psychology
- Behavioral Genetics
- Clinical Pharmacology
Expert & Researcher Feedback

What do you feel were the CEs' contribution to the research project?

- Ideas for community benefit
- Ideas for community's project awareness
- Participant recruitment ideas
- Appropriatentess feedback
- Feasibility feedback
- Increased researchers' community sensitivity
- Increased researchers' community understanding

![Bar chart showing contributions from researchers and experts](chart.png)

- Researchers (19)
- Experts (109)
Summary

- Proven method for meaningfully engaging community members
- Establishing infrastructure is necessary for sustainability of community-engaged efforts
- Appropriate compensation standards for experts must be developed and implemented
- Community engagement is appropriate and necessary in all stages of research
- CES model easy to replicate and adaptable in varied contexts
- Not a community advisory board, but opportunity to actively engage community and receive input
How to establish your own CES program

- Contact Yvonne Joosten, MPH
- The studio can be demonstrated on site to coordinating staff
- An in-depth toolkit is available to guide staff through a step-by-step process, training of researchers and community experts, presentation templates, needed materials, expected budget and FAQs
Contact

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