COMMUNITY ENGAGEMENT IN THE CTSA PROGRAM: STAKEHOLDER RESPONSES FROM A NATIONAL DELPHI PROCESS

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In Fall 2012, Congress mandated an independent assessment of the CTSA program. An ad hoc expert committee convened by the Institute of Medicine (IOM) assessed the efficacy of the overall program and provided future guidance.
The CTSA Program

- National Institutes of Health (NIH) launched the Clinical and Translational Science Award (CTSA) program in 2006

- **Goals**: facilitate research and its translation into real world settings

- 2012 program budget: $461,000,000
The Delphi Method

- An exploratory method designed for group consensus building developed in 1950 by the RAND corporation.

- Steps:

  1. Initial survey/questionnaire presented to diverse panel of experts
  2. Facilitator analyzes key themes and associated rationales
  3. Initial questions and responses are sent back to the group
  4. Group responds, giving consideration to summary of themes and rationales provided by facilitator
  5. Process continues until the group nears consensus
The CCHERS-CCPH Delphi

Delphi conducted in February 2013 through a partnership between Center for Community Health Research and Service, Inc. (CCHERS) and Community-Campus Partnerships for Health, Inc. (CCPH) Objectives:

- Gain a deep, contextualized understanding of stakeholder perceptions of community engagement as a CTSA priority
- Operationalize and improve community engagement
- Explore appropriate metrics for community engagement
The Participants

- Invitees (n=250) were recruited from:
  - CCPH-CTSA Member Interest Group
  - National Community Partner Forum participants
The Process

- **Round 1**: 6 open-ended items:
  - Why should community engagement be a priority?
  - How can the CTSA program be improved to more fully engage partners?
  - What are the benefits to community engagement?
  - What are the current gaps and barriers associated with engagement?
  - What metrics are being used to assess community engagement?
  - What metrics *should* be used to assessment community engagement?

- **Round 2**: Respondents rate level of agreement with each of the choices on a 4-point Likert scale

- **Round 3**: Respondents rank Round 2 items in terms of potential impact on CTSA program and implementation feasibility
## Results: Participation

<table>
<thead>
<tr>
<th>Participants</th>
<th>Round 1</th>
<th>Round 2</th>
<th>Round 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number Responding</td>
<td>n=59</td>
<td>n=83</td>
<td>n=40</td>
</tr>
<tr>
<td>Community Partner</td>
<td>45%</td>
<td>52%</td>
<td>50%</td>
</tr>
<tr>
<td>Institution-Based Researcher</td>
<td>24%</td>
<td>19%</td>
<td>19%</td>
</tr>
<tr>
<td>Institution-Based Staff</td>
<td>14%</td>
<td>14%</td>
<td>22%</td>
</tr>
<tr>
<td>Stakeholder</td>
<td>5%</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>22%</td>
<td>18%</td>
<td>15%</td>
</tr>
</tbody>
</table>
Results: Why community engagement should be a priority

- Four key themes:
  - Makes the translation of results more likely
  - Ensures relevance and applicability of research to concerned communities
  - Engenders trust in the community for research and researchers
  - Improves participants recruiting and retention

- “The ultimate success of the entire health research enterprise depends on individuals and communities embracing and adopting the new scientific knowledge that it produces. The research process itself will ultimately be more productive if individuals and communities identify their priority problems and proposed solutions and, thus, frame the research questions themselves.”
Results: Six key areas of improvement for community engagement

Themes were ranked on a scale of 1-6 for potential degree of impact and feasibility

<table>
<thead>
<tr>
<th>Themes from Open-Ended Response</th>
<th>Impact</th>
<th>Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide sufficient <strong>funding</strong> for community outreach, including better compensation for community partners</td>
<td>4.52</td>
<td>3.18</td>
</tr>
<tr>
<td>Include specific <strong>expectations</strong> for what CE must involve</td>
<td>3.85</td>
<td>4.43</td>
</tr>
<tr>
<td>Include specific expectations for what CE must involved in funding criteria for CTSAs</td>
<td>3.42</td>
<td>4.02</td>
</tr>
<tr>
<td><strong>Integrate</strong> CE into each core rather than keep separate core</td>
<td>3.53</td>
<td>3.71</td>
</tr>
<tr>
<td>Provide <strong>education and training</strong> to institutional partners concerning the importance of community engagement</td>
<td>3.25</td>
<td>2.79</td>
</tr>
<tr>
<td>Offer <strong>research literacy training</strong> to community partners</td>
<td>2.52</td>
<td>2.85</td>
</tr>
</tbody>
</table>
Results: Benefits of engaging community organizations and patient advocacy groups

“Community organizations can also help tailor the research questions, research design, and use of the research findings to better serve the needs of the community”

- Visibly improves health outcomes and addresses disparities
- Improves relevance and efficacy of the research
- Builds trust between community and institutions
- Improves recruitment and retention of participants, group is more representative of population of focus
Results: Barriers to meaningful engagement, impacts, and feasibility to address

<table>
<thead>
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<th>Themes from Open-Ended Responses</th>
<th>Impact</th>
<th>Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional partners do not <strong>respect</strong> the value of community engagement in research</td>
<td>4.23</td>
<td>4.05</td>
</tr>
<tr>
<td><strong>Inequitable treatment</strong> of community partners in distribution of funding and in governance/leadership roles</td>
<td>3.79</td>
<td>3.64</td>
</tr>
<tr>
<td>There is little or no <strong>funding</strong> for compensation of community partners</td>
<td>3.76</td>
<td>4</td>
</tr>
<tr>
<td>Established academic culture does not have proper <strong>protocol</strong> for engaging community partners</td>
<td>3.56</td>
<td>3.43</td>
</tr>
<tr>
<td>Members of the community <strong>distrust</strong> the institutions performing the research</td>
<td>3.45</td>
<td>2.9</td>
</tr>
<tr>
<td>There is little or no <strong>funding</strong> for research literacy training for community partners</td>
<td>2.18</td>
<td>2.95</td>
</tr>
</tbody>
</table>
Results: Metrics being used to measure progress of CTSA program in community engagement

- “I don't think there are any established and unified metrics that are being used to measure CE across CTSA programs. There's been a lot of discussion but I don't think any things has been determined or adopted. This hurts CTSA CE programs ability to measure, document, communicate their value in a way that's understood by CTSA leadership—locally and nationally”

- “The CTSA program appears to depend on conventional metrics that are easily quantified: grant dollars awarded and manuscripts published. This will show an increase in the amount of research, but will not indicate the degree to which the research is translational.”

- Measures that may get at community engagement are being used by CTSA's, but they are not analyzing impact
Results: Metrics that *should be* in place to measure progress of CTSA program in community engagement

<table>
<thead>
<tr>
<th>Themes from Open-Ended Responses</th>
<th>Meaningfulness as Measure</th>
<th>Likelihood of Progress in 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of <em>integration</em> of community partners in the research team</td>
<td>3.59</td>
<td>3.36</td>
</tr>
<tr>
<td>Documented research <em>outcomes</em> (translation, community health outcomes, policy changes, etc.)</td>
<td>3.43</td>
<td>3.00</td>
</tr>
<tr>
<td>Allocation of <em>funds</em> to community partners and other non-academic stakeholders</td>
<td>3.26</td>
<td>2.95</td>
</tr>
<tr>
<td>New and sustained community <em>partnerships</em></td>
<td>2.79</td>
<td>2.90</td>
</tr>
<tr>
<td>Number of new <em>projects</em> initiated</td>
<td>1.92</td>
<td>2.79</td>
</tr>
</tbody>
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Discussion

- Skepticism among respondents regarding feasibility of strengthening CTSA community engagement

- Why the doubt?
  - Community engagement was not explicitly required in the last CTSA funding announcement
  - Lack of value placed on real and potential contribution of community partners to research—inclusive of the lack of compensation for their time and expertise
Implications: Recommendations for NCATS

- Make a strong and unequivocal statement of support for community engagement as essential to conducting and applying the results of clinical and translational research

- Include community partners in CTSA governance, decision-making, and professional development
Implications: Recommendations for NCATS

- Invest in assessing the impact of community engagement
- Ensure fair and equitable peer review
- Make a strong and unequivocal statement of support for community engagement as essential to conducting and applying the results of clinical and translational research
- Include community partners in CTSA governance, decision-making, and professional development
Conclusions

- Community Engagement
- Buy-in at multiple levels
- Sustaining support
References


NCATS. About the CTSA Program. 2012 [cited 2013 July 1]; CTSA website.


