It’s Time to Fully Realize the Potential of Community Engagement in the CTSA Program

Remarks to the IOM Committee to Review the CTSA Program at NCATS
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Community-Campus Partnerships for Health
Mission

To promote health equity & social justice through partnerships between communities & academic institutions
CTSA Connections

CCPH-CTSA Member Interest Group
About 80 people from 34 CTSA and 2 CTSA applicants

Community Network for Research Equity & Impact
About 200 community leaders; 30% of whom are involved in CTSA and 80% in federally funded research

CTSA Partnerships
Washington University – Sentinel Network
Indiana University – CORUS Website
Vanderbilt University – Communityresearchpartners.net
Albert Einstein – Community Partner Forum, CES4Health.info
Northwestern – Mock grant review panel & grantwriting technical assistance
Community Partners Integration Workgroup – Community inventory
Input into Future of the CTSA Program

4/6/12 response to RFI on Enhancing the CTSA Program

9/28/12 letter to NCATS Director Dr. Austin during his 1st week on the job

11/15/12 response to RFI on Enhancing Community-Engaged Research

12/3/12 call with NCATS Acting Division Director
In research, community engagement is a **process of inclusive participation** that supports mutual respect of values, strategies and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest or similar situations to address issue affecting the well-being of the community of focus.

**Community engagement is a core element of any research effort involving communities.** It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment before, during and after the research.

NIH Council of Public Representatives, 2008
Successful translation of science into improved population health requires community support and involvement at every level – from volunteers who participate in clinical trials, to physicians and other health providers and community leaders who assist their neighbors in behavior change, to community-based organizations and engaged citizenry who instigate political and policy change.

As the CTSA program transitions to NCATS, the [Senate Appropriations Committee] urges the NIH Director to ensure that the current focus on the full spectrum of translational research is maintained. The inclusion of patient-centered outcomes research, community engagement, training, dissemination science and behavioral research is extremely important to... the success of the CTSAs.

Committee report that accompanied NCATS budget in Consolidated Appropriations Act of 2012
BENEFITS & SUCCESSES OF COMMUNITY ENGAGEMENT IN THE CTSA PROGRAM

- Increased trust in research institutions, researchers and research
- Increased science, research & health literacy
- Culture of inquiry and evidence-informed decision making
- Research priorities and investments that are responsive to community-identified concerns
- Culturally appropriate and ethical study designs
- Consideration of community risks and benefits
- Recruitment and retention of informed study participants
- Culturally appropriate applied tools and resources
- Greater community ownership and power in the research process
- Successful community-based health interventions

*Sustained investments can lead to mutual benefits*
BUT THERE ARE CHALLENGES...

• Lack of understanding and consensus on the “why”
• “Partnerships” that serve institutional agendas
• Community partners as study promoters and recruiters
• Community partners not adequately compensated
• Inadequate support for training & mentoring all around
• Lack of accountability for partnership principles, MOUs
• Lack of transparency in decision making, unilateral decision making
• Withdrawal of support for community engagement
• Community engagement silo
• Community partner fatigue
• Community engagement and community-engaged research not viewed as rigorous
...this FOA is designed to provide institutions with greater flexibility and more opportunities to build on institutional strengths. NCATS continues to expect all sites to provide core resources for the entire spectrum of translational research.

FAQ, RFA-TR-12-006, Institutional Clinical and Translational Science Award (U54), 2012

NCATS defines translational research broadly to include the early steps necessary to develop new therapeutics, devices and diagnostics from basic discoveries, the steps necessary to establish real world efficacy, and the research needed to improve the practical implementation and dissemination of improved approaches to care. This breadth is sometimes described as T1 through T4.

RFA-TR-12-006, Institutional Clinical and Translational Science Award (U54), 2012
Support Community Engagement as Central to the CTSA Mission & Successful Translational Research

Community engagement is essential to the CTSA’s ability to bring better health to our communities – but this is not reflected in the RFA nor the NCATS definition of translational research

• Require community engagement in the CTSA program, with corresponding review criteria and review panel
• Make community engagement explicit in the definition of translational research – and engage communities in that re-definition
Invest in Critical Infrastructure for Community Engagement & Community-Engaged Research

Just as having funding for lab space & supplies is crucial to successful basic science research...

- Invest in developing & sustaining community-academic research partnerships
- Invest in research capacity and infrastructure in communities
- Invest in training, mentoring and research funding for investigators and partners
- Link and leverage community engagement across CTSAs located in the same city/region
- Invest in participatory assessment of impact of community engagement and the factors that hinder/accelerate – and act on the findings!
Ensure Community Participation in Priority-Setting and Decision-Making

*NIH is impenetrable to community partners*
*Community partners must have a voice*

- Invest in equitable governance and transparent decision-making
- Ensure equitable and fair peer review
- Make the investments needed to ensure meaningful community participation on advisory councils, grant review panels, policy-making bodies, CTSA committees, etc.
Don’t Reinvent the Wheel

*In 1995, the National Institute of Environmental Health Sciences launched the first research initiative at NIH specifying the use of the CBPR approach...*

Mobilize and leverage existing knowledge, assets and resources
- Within the CTSA program
- Within NIH and the federal government more broadly
- The private sector
- Other countries
FOR MORE INFORMATION

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