Community Engagement & Research

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Objectives

1. Infuse patient-centered, community-engaged research across the translational research spectrum to strengthen the links among research discovery, bidirectional translation, and implementation.

2. Provide community engagement expertise and support to increase the translational research workforce and build the capacity of researchers, community organizations and clinical practices to conduct community-engaged research studies that can rapidly improve health in our communities.
Objectives

3. Reduce health disparities in the Rocky Mountain Region through targeted investments in community translational research and dissemination of successful practices.

4. Develop & transform institutional structures and resources to support and enable sustainable community-academic research partnerships.
Approach

Objective 1: Infuse patient-centered, community-engaged research across the translational research spectrum.

Community Research Consults

- Infuse community input into the early design of T1-T4 research studies to ensure responsiveness to the patient and community needs.
- Builds a cadre of community members, patients and other stakeholders available for ongoing engagement in the research enterprise.
Approach

Community Research Consults

- Enhance the translational potential of T1 research
- Community consults engage diverse stakeholders early in research process
- Enhance feasibility of study designs, generalizability of findings, salience of clinical endpoints

Source: cctsi.ucdenver.edu
Approach

Objective 2: Provide community engagement expertise and support to increase the workforce and build capacity.

*Education and training for academic researchers*
- Introduction to CBPR for Community-Academic Partnerships: Let’s Get Started
- Colorado Immersion Training in Community Engagement
- Research Through Community-Academic Partnerships Seminar Series
- Engaging Communities in Education and Research (ECER) Annual Conference
Approach

Objective 2: Provide community engagement expertise and support to increase the workforce and build capacity.

Boot Camp Translation

• Engagement methodology
• Facilitator Training

Engagement Assistance

• TA and guidance for investigators seeking PCORI funds

Community/Patient Advisory Boards

• TA & Training on developing CABs
Approach

Objective 2: Provide community engagement expertise and support to increase the workforce and build capacity.

Community Research Liaisons

• Cultivate relationships between academic researchers and communities
• Identify community health priorities and design locally relevant studies that address real patient and provider needs.
Approach

Objective 3: Reduce health disparities through targeted investments in community translational research and dissemination.

CE Pilot Grant Program

• Supports community-academic partnerships to perform pilot studies that strengthen relationships and produce preliminary data for future competitive grant applications.

• Supports the development of innovative interventions or the adaptation and implementation of existing discoveries and evidence into the community setting.
Approach

Objective 4: Develop/transform institutional structures and resources to support sustainable community-academic research partnerships.
Approach

Objective 4: Develop/transform institutional structures and resources to support sustainable community-academic research partnerships.

PACT & PACT Council
• Statewide collaborative of academic researchers, community-based organizations and individuals, and healthcare provider networks working together to provide a platform for innovation in community engagement.
Approach

Objective 4: Develop/transform institutional structures and resources to support sustainable community-academic research partnerships.

Practice Based Research Networks

- PBRN’s have been engaged as close collaborators in the CE&R Core’s efforts to examine the benefits of community engagement in practice-based research.
- We have started to more closely link the infrastructure of the CE and PBRN programs, investing in two shared staff positions and submitting a $15 Million grant proposal to AHRQ.
Approach

Objective 4: Develop/transform institutional structures and resources to support sustainable community-academic research partnerships.

The Colorado Foundation for Public Health and the Environment (CFPHE)

• Serves as an administrative & programmatic liaison between the University and Community
• Create efficiencies in the distribution of funding and other resources to community-based partners.
Because university, state and federal agencies often have cumbersome administrative and contractual requirements, they have limited ability to adjust to the needs of community based organizations that have been engaged as research partners, rather than research subjects.

The CCTS and CFPHE have established administrative systems that allow meaningful community representation and participation in the research enterprise.

- Acts as an administrative and fiscal intermediary for community partners.
- Assists community members in their efforts to promote and conduct research and provides community based infrastructure for research activities.
- Ensures the needs of both the academic and community partners are supported fiscally and programmatically.
- Creates efficiencies in the distribution of funding and to improve responsiveness to community administrative needs.
- Enhances community capacity to navigate the administrative and institutional requirements of working with a large institution.
- Allows agencies with little cash flow to participate in cost reimbursable grant projects.
Y2 Budget Challenges

- Reduced number of PACT Council members
- Reduce PACT Compensation
- Re-evaluating payment model
Response to Budget Challenges

- Reduced operating expenses mainly in cuts to dissemination activities
- Leveraged other resources to reduce staff time charged to the grant
- Re-evaluating the amount of FTE on the scientific staff
Accomplishments

Objective 1. Infuse patient-centered, community-engaged research across the translational research.

• We have conducted two community consults and are working closely with the PACT Consults Committee to ensure that there is a clear implementation and evaluation process for the consults as we move forward.
• Working closely with the CCTSI Ethics Committee and others providing similar services to ensure that our efforts are complimentary, rather than duplicative.
Accomplishments

Objective 2. Provide community engagement expertise and support to increase the workforce and build capacity.

Education and training for academic researchers

• 10 academics and 11 community members completed the Introduction to CBPR for Community-Academic Partnerships Training. Eleven CE staff, liaisons and others assisted in conducting the training.
• 12 people participated in the Colorado Immersion Training in Community Engagement.
• More than 600 people participated in the Engaging Communities in Education and Research (ECER) Annual Conference.
Accomplishments

Objective 2. Provide community engagement expertise and support to increase the workforce and build capacity.

Boot Camp Translation
• We have conducted more than 12 BCT’s both in and out of state over the past year, translating evidence based guidelines for multiple medical conditions into community-relevant language and constructs.

Facilitator Training
• Conducted two 16-hour training for facilitators, medical professionals, coordinators and co-facilitators. There were a total of 17 participants: 50% academic and 50% community who came from both coasts of the United States and representative communities in Colorado.
Accomplishments

Objective 2. Provide community engagement expertise and support to increase the workforce and build capacity.

**Engagement Assistance**
Provided direct TA to multiple investigators seeking PCORI funds.

**Community/Patient Advisory Boards**
- Provided direct TA to multiple organizations, including the VA, on developing and managing community and patient advisory boards.
Accomplishments

Objective 3. Reduce health disparities in the Rocky Mountain Region through targeted investments in community translational research and dissemination.

• Our pilot grant program continues to yield valuable community engaged research projects that go on to procure national recognition. For example, a pilot project on Hands-Only CPR was recently published in the Annals of Emergency Medicine and launched a website in partnership with the American Heart Association.

• This is the first paper ever written on this topic, in a journal that RARELY publishes qualitative work. This foundational work will provide the framework for a national program targeting decreasing health inequities in cardiac arrest.
PROGRAM OVERVIEW

Cardiac arrest occurs when the heart stops and can no longer pump blood to the brain and other organs. Nearly 300,000 people in the United States suffer a cardiac arrest each year. Without immediate CPR, 420,000 people will die each year. The American Heart Association reports that only 1 in 10 cardiac arrest victims survive.

Where you live matters! People who live in African-American, Hispanic, and low-income communities are more likely to die from a cardiac arrest. In fact, African-American and Hispanic communities are also 13% less likely to have someone stop and perform CPR.

WHAT IS THE AHA DOING?

We are excited to launch the new Hands-Only CPR Program! Using your community’s data, the program can tailor training to the neighborhoods where it can make the most impact.

Phase 1: Identify
Use data to identify high-risk neighborhoods and sites for targeted CPR education and training.

Phase 2: Implement
Work with local high-risk neighborhood residents to implement a train-the-trainer CPR educational program.

Phase 3: Track
Track how many CPR trained and trained on you.

SPECIAL CONTRIBUTION

The HAN DDS Program: A Systematic Approach for Addressing Disparities in the Provision of Bystander Cardiopulmonary Resuscitation

Cornilla Saxson, MD, MS, Jason S. Haukoos, MD, MSc, Brian Elgee, PhD, and David J. Magid, MD, MPH

Abstract

The current paradigm of bystander cardiopulmonary resuscitation (CPR) blankets a community with training. Recently, the authors have found that high-risk neighborhoods can be identified, and CPR training can be targeted to the neighborhoods in which it would have the greatest impact. This article presents a novel method and pilot implementation trial for the HAN DDS (Identifying High-Risk Neighborhoods to Decrease Disparities in Survival) program. The authors also describe a three-step approach: identify, implement, and evaluate. This systematic approach to solving the problem of CPR training in these neighborhoods. The HAN DDS program is a systematic approach to implementing a community-based CPR training program. Further research is currently being conducted in four large metropolitan U.S. cities to examine whether these results from the HAN DDS program can be successfully replicated in other locations.

Accomplishments

Objective 3. Reduce health disparities in the Rocky Mountain Region through targeted investments in community translational research and dissemination.

- Our pilot grant program and partnership with CFPHE serves as a national model for PCORI’s Pipeline to Proposal Awards initiative.
- In addition to our pilot program serving as the programmatic model for the P2P awards, PCORI selected CFPHE as the nation’s first regional Pipeline Awards Program Office (PAPO) to serve the Western region of the U.S.
- CFPHE and the CE Core assisted PCORI in developing the PAPO model and selecting/training 4 additional PAPOs around the country – linking PCORI to the National Network of Public Health Institutes.
Accomplishments

Objective 4. Develop & transform institutional structures and resources to support and enable sustainable community-academic research partnerships.

- Throughout the funding period, the CE&R Core has continued to support the PACT and its governing board, the PACT Council, evaluating our work, refining our aims, developing metrics, strengthening our infrastructure and improving the programs and services we provide.
- Our innovative partnership with CFPHE has greatly improved the CE&R Core’s ability to respond to community administrative needs and has been presented at several national conferences. It has also gained the recognition of PCORI as a model for their own community pipeline awards program.
Accomplishments

Objective 4. Develop & transform institutional structures and resources to support and enable sustainable community-academic research partnerships.

• We have started to more closely link the infrastructure of the CE Core and PBRN programs, investing in two shared staff positions and submitting a $15 Million grant proposal to AHRQ.

• We have started developing a business plan to address sustainability and financial viability for the CE Core’s most successful programs and services. We will continue these efforts throughout the grant period.
Accomplishments

Objective 4. Develop & transform institutional structures and resources to support and enable sustainable community-academic research partnerships.

• Working to identify and address institutional barriers to Community Engagement in research
  – Administrative
  – Regulatory (IRB)
  – Career development
National CTSA Consortium Involvement

List individuals in your Core/Program involved in the national CTSA Consortium Working Groups.

• Fernando Pineda-Reyes, the Vice Chair of the PACT Council, was appointed to the NCATS Advisory Council Working Group on the Institute of Medicine's (IOM) Clinical & Translational Science Award Program Report. He was the only community representative on this NIH advisory council.

• Fernando has served on the planning committee for all three National Community Partner Forums on Community-Engaged Research and has served on the PACT council for the Community Engagement Core of the CCTSI since its inception.
National CTSA Consortium Involvement

Don Nease, Director is now on the newly formed Collaboration/Engagement Domain Task Force
Response to EAC Critiques

• “We would encourage this (Boot Camp Translation for Patient-Centered Outcomes) to be expanded to allow not just for uptake but also for adaptation and evaluation locally for their fit.”

• The major recommendation from last year that appears to need renewed consideration is the development of metrics for evaluation of the Community Engagement and Research Core that measure more than individual level participation.

• Finally, the issue of community “research fatigue” raised concerns that need to be addressed around incentives and rewards for the community volunteers who have made the Community Engagement component of the CCTSI so successful to this point.

• Through PCORI funding we have conducted over 12 BCT’s, 3 trainings and are completing a comprehensive evaluation. New PCORI funding is being sought to further disseminate BCT’s. PACT Council is leading business model planning around BCT training and dissemination.

• We have developed a comprehensive logic model to assist in developing and defining outcomes beyond the community level. Next slide details this logic model.

• Our Community Consult and Ethics committee, comprised of academic and community members, continues to push this discussion forward. Our Community Research Liaisons also revised their scope of work and job description taking the potential for “research fatigue” into account.
# Response to EAC Critiques

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<th><strong>Outcomes -- Impact</strong></th>
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<td><strong>Internally-focused</strong></td>
<td><strong>Short (1-2 years)</strong>: Stakeholders are empowered through timely access to information. People and partners feel they can fulfill their role(s) effectively. Norms and operating agreements are established that support the integration of CBPR principles in operations. People/partners operate in accordance with CBPR principles (includes administrative integrity and transparency). Individual capacity of partners is effectively engaged. Partners perceive their engagement as mutually-beneficial/impactful.</td>
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<td><strong>Medium (3-4 years)</strong>: Policies, procedures (including the process of development) reflects fidelity to CBPR principles. Enhanced accountability (achieved through quality assurance; transparent, evidence-informed decision-making; and, rigorous assessment of program outcomes).</td>
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<td><strong>Long (5+ years)</strong>: A streamlined infrastructure exists for the cost-effective implementation of mission-critical activities. Sustained, dependable funding streams have been established. Stable administrative and governance structures. Enhanced trust and transparency (e.g., regarding decision-making processes). Sustainable resources and services (including research liaisons).</td>
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<td><strong>Externally-focused</strong></td>
<td>Needs of research community (whether academically or community-based) are proactively addressed (indicator of the quality and adequacy of activities). Enhanced political capital (e.g., to affect policies in organizations). Individuals find a role/niche that allows them to actualize enhanced capacity for CBPR (e.g., participation/engagement changes career trajectories). Dissemination and implementation of resources, services, practices, policies informed by broad stakeholder perspectives. Resources/services/programs have a national reach.</td>
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- Institutional policies are supportive of community engagement in the research enterprise (e.g., promotion and tenure). Sustainable engagement (with attention given to mitigating the effects of community research fatigue). Collective impact. Public trust (Wallerstein trust scale). Improved community health status indicators.
Questions for EAC

• PACT Council is engaging with the Director and staff in business model planning for BCT, Immersion and other programs in the light of declining resources and new directions of NCATS.
  – What opportunities should we be taking advantage of to promote sustainability beyond traditional grant funding?
  – What threats should we be aware of?