

**“Across CTR Programs: Issues in Community Engaged Research Development”
February 19, 2015, 12:45PM-2:15PM**

1. Mountain West IDEa Clinical Translational Research – Infrastructure Network (CTR-IN)

Robert Langer, MD MPH and Bert Boyer, PhD

- 7 states including: New Mexico, Nevada, Montana, Arizona, Hawaii, Alaska, Colorado
- Native Americans and other pilot grants
- Similar to other CTRs in terms of issues/community mandate
- Q & A
 - There is a tech working at each of the lab sites
 - Cultural and diversity training is completed by the staff during a two day workshop
 - In Alaska, the consent process occurs by submission of proposal from university, then group study, which is also known as the tribal review board
 - Aim 1: Example of how to work/experience by development of case study. If there is a 20k grant and a death occurs, will you stop collecting data? How do you data date that process?

Center for Alaska Native Health Research

- COBRE funded in 2001, rural Alaskan communities
- AI/AN Community Engagement
 - Partnerships take time and require frequent face-to-face interaction
 - Interaction to expand epigenetics, increase ability to work, and decrease health disparities
- AI/AN CTR Application
 - Site directors at UAF, MSU, UM, and SCF
 - Aim 1: Case study curriculum development to facilitate education, training and mentoring
 - Aim 2: Clinical Site Navigators to facilitate clinical and translational research in AI/AN settings

2. Louisiana Clinical and Translational Science Centers (LACaTS)

Stephanie Boyles, PhD

- Funding
 - 10% of effort for several faculty and 100% of effort for one specialist, who provides training materials and recruits researchers
 - No additional funding for community-engaged research grants
- Challenges
 - No mechanism to support community-engaged research
 - Have lots of researchers doing community-engaged research, but already have their own networks
 - Need additional support for Community Advisory Board
 - Struggle to understand or define clinical and translational research
- Opportunities
 - Strong community ties including state and small community organizations
 - Local advisory board
- Successes
 - Helping researchers in recruiting
 - Troubleshooting issues

- Use of technology that matches researchers with projects
- Future Objectives
 - Develop training materials for researchers on community-engaged research
 - Identify researchers that match a proposed community engagement research idea
- Q & A
 - There is no educational training in place yet , but the goal is to use CBPR materials for translation to educate researchers on community research
 - The training would not be just for researchers, but the power points/training materials would be available on the website available to the public
 - Frustration: there are ideas but no \$ or funding mechanism
 - Comment: Need to use the education and mentoring KCAs to feed information from other components
 - Trust is extremely important to obtain from your community
- **Oklahoma Shared Clinical and Translational Research Centers (OSCTR)**
James Mold, MD MPH
 - \$15M grant
 - Health improvement/idea within the proposal for quality improvement
 - Practice-based network, added Pharmacy, Pediatrics, and Indians
 - Coordinator needed for networking
 - Specific Aims
 - Aim #1: Strengthen/expand processes that bring researchers and practitioners together to find solutions to health/healthcare problems and translate innovations from research into practice
 - Aim #2: Increase the capacity of community test sites by strengthening and expanding practiced-based research networks (PBRNs)
 - Aim #3: Facilitate construction of a statewide community-based dissemination/implementation infrastructure
 - Aim #4: Provide support and assistance to the University of Arkansas for Medical Sciences and the Arkansas Area Health Education Centers
 - Aim #5: Provide support and assistance to the OCA Inter-Tribal Health Board, which includes 55 tribal and HIS health systems which span across Oklahoma and Kansas
- **South Carolina Clinical & Translational Research (SCTR)**
Carolyn Jenkins, DrPH RD APRN FAAN
 - Engagement process. Couple comparison where research is the marriage
 - Key Successes
 - Launched CBPR Research on Campus
 - Community Engaged Scholars highlighted in IOM Report
 - Are We Ready - community research toolkit
 - Team Science & Dissemination Science
 - Bridging Science & Community in Bamberg (Diabetes)
 - Community and Scientific Retreats

- Research Summit: Sea Islands Population
- Obesity Evidence Academy
- CER Interest Group and Scientific Retreat
- PCORI Workshop
- Challenges
 - Expanding from local communities to statewide
 - Integrating community-engaged research through T1-T4 and how it will work with the community
 - Lack of measurement instruments
 - PCORI is a real challenge and how to align/understand community-engaged research
- Community Engaged Scholars (CES-P)
 - Community engaged research topics include: Community problem identification, Data collection and analysis, Evaluation, Translation and dissemination
 - Total of 20 teams completed CES-P over 5 years
- Future Objectives
 - Integrate community-engaged principles across all SCTR Programs and share innovative practices with other CTSA's
- Q & A
 - University partnerships, wish to have a true match with community researchers priorities within the university and working closely with community advisory board and big data
 - T1 work should be more aggressive to ring other steps together
 - Currently in progress of working harder in T1. Researchers are to state what their goals and aims are through a system called [Donors Cure](#)
 - Discussions have community generate ideas then to break down T1-T4
 - How do you engage by doing the most care? Sharing of research network resources is important. Need to develop relationships, solve problems by facing challenges, and integrate microeconomics into the project
 - The best approach is to start by engaging a small group (approx. 11-12 people). Identify the priorities and needs by using a community-engaged researcher and receiving input from stakeholders.
 - It is important to engage multiple stakeholders in an organized way
- **Delaware Clinical and Translational Research ACCEL Program**
Michael Rosenthal, MD
 - This discussion was important to determine how we can use/hear ideas across the CTRs
 - It is important to understand the value of the community and to do this using a common voice
 - We need to engage researchers just as much as the community. There is potential to do so by using our current community programs that need researchers for evaluation
 - Next step is how to advance this work into NIH or government grants

*5/18/15: Community Engagement and Outreach Conference,
Chase Center on the Riverfront, Wilmington DE [www.de-ctr.org]*