Strategies to Engage Community Partners in Research used by Delaware-CTR ACCEL

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ABSTRACT

Community-engagement is a key step in conducting research which is impactful for patients and communities. The Delaware Clinical and Translational Research (DE-CTR), Accelerating Clinical and Translational Research (ACCEL) program has implemented several successful approaches to engage our community, and to educate and motivate our researchers in this area. Increased participation in community-engaged research and community-based participatory research was accomplished through DE-CTR/ACCEL using multiple methods detailed in this manuscript. The community engagement infrastructure has fostered community involvement in translational research including capacity development, implementation, evaluation and dissemination.
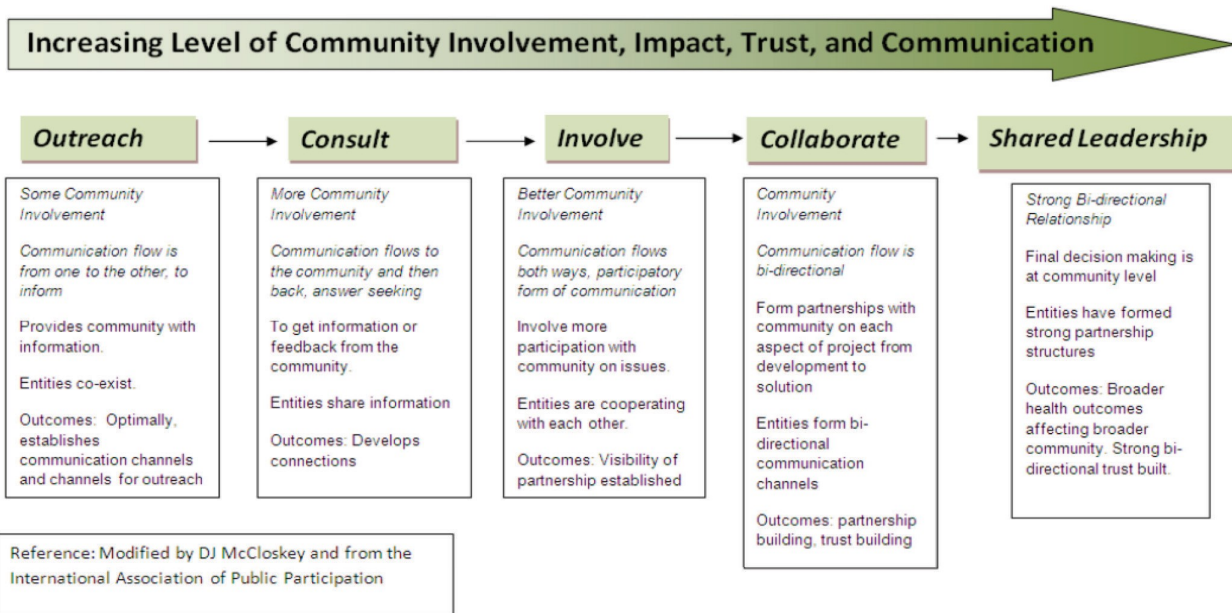
Academic-community partnerships for research, such as those implemented in ACCEL will be crucial to addressing health disparities and health priorities.

BACKGROUND

In 2013, four institutions: University of Delaware, Christiana Care Health System, Medical University of South Carolina, and Nemours Alfred I DuPont Hospital for Children were awarded a five year Clinical and Translational Research (CTR) award from the National Institutes of Health, National Institute of General Medical Sciences. Thus, the Accelerating Clinical and Translational Research (ACCEL), Delaware-CTR program was formed consisting of seven different components, including an innovative Community Engagement and Outreach (CEO) component. The CEO component is tasked to engage community organizations, primary care practices, statewide activities and investigators in collaborative, creative models of clinical and translational science research. The purpose of this engagement is to create research that is truly impactful for patients and communities. Funding through CEO has supported research awards, community-research activities, and personnel focused on expanding research to address the health priorities of the Delaware community.

Community engagement often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.[1] Figure 1 depicts the continuum of community engagement and establishes increasing levels of community engagement towards the desired outcome of shared leadership, and was a working model for the CEO component of the ACCEL program.

Figure 1. Community Engagement Continuum[2]

Increasing Level of Community Involvement, Impact, Trust, and Communication

Outreach	Consult	Involve	Collaborate	Shared Leadership
Some Community Involvement	*More Community Involvement*	*Better Community Involvement*	*Community Involvement*	*Strong Bi-directional Relationship*
Communication flow is from one to the other, to inform	*Communication flows to the community and then back, answer seeking*	*Communication flows both ways, participatory form of communication*	*Communication flow is bi-directional*	Final decision making is at community level
Provides community with information.	To get information or feedback from the community.	Involve more participation with community on issues.	Form partnerships with community on each aspect of project from development to solution	Entities have formed strong partnership structures
Entities co-exist.	Entities share information	Entities are cooperating with each other.	Entities form bi-directional communication channels	Outcomes: Broader health outcomes affecting broader community. Strong bi-directional trust built.
Outcomes: Optimally, establishes communication channels and channels for outreach	Outcomes: Develops connections	Outcomes: Visibility of partnership established	Outcomes: partnership building, trust building	

Reference: Modified by DJ McCloskey and from the International Association of Public Participation

To expand community engagement across the DE-CTR/ACCEL institutions and across the State of Delaware, the CEO component developed specific aims as follows:

1) Establish a new infrastructure to actively involve the community in setting clinical and translational research priorities,

2) Develop new community-institution partnerships in clinical and translational science; and

3) Identify, educate, and prepare community leaders, healthcare providers, and institutional researchers in the principles and practices of community-engaged research (CEnR).

Over the course of the first three and a half years of funding (September 2013-November 2016) the CEO component developed and implemented a strategic plan to achieve its specific aims. In this paper, we describe the details of the strategic plan, its implementation, and lessons learned.

METHODS

Community Engagement and Outreach (CEO) Leadership

At least one lead from each institution was selected with the intent to include individuals with prior research experience, as well as, established community- academic partnerships. In addition to the institutional leads, the CEO team included 20 individuals: members of the hospitals' community outreach and prevention programs, social scientists, clinicians, and representatives of the Delaware Division of Public Health. A community-based consultant was engaged to help recruit a community advisory council. The chair of the council participates in ACCEL leadership meetings and continues to be instrumental in decisions made through the CEO component. In order to confirm that CEO members are represented at key community meetings across the State of Delaware, a survey[3] was developed through REDCap (Research Electronic Data Capture) to poll the component, and responses identified 28 different community meetings in which members attend, representing good diversity geographically and topically.

Community Advisory Council (CAC)

The CAC was formed consisting of 15 diverse members from organizations across all 3 counties in Delaware including: the state university, regional health coalitions, community-based organizations, federally- qualified health centers, community clinicians, the state government, and faith-based organizations. Leaders within ACCEL and the CEO nominated individuals and reached out for additional nominations. Members were to have interest in clinical translational research issues, to be able to review and disseminate research, and to be able to work collaboratively to develop approaches to solve problems. The ideal member would be an advocate, a recognized key opinion leader and an influencer of multiple constituencies. The committee has had a vital role in establishing and maintaining bi-directional communication, and development between the community and DE-CTR/ ACCEL program. Early accomplishments of the CAC included selection of a chair, training of the CAC membership in the overview of ACCEL and its purpose, and development of an action plan aligned with the strategic plan of CEO.

In order to strengthen communication and spread the word about ACCEL, the CEO and CAC developed a One Voice kit, a power point presentation with a clear, consistent, and compelling way to explain the DE-CTR/ ACCEL program across all audiences. In addition, a Principles of Partnership imagery presentation was developed that included common pictures tied to the community-based participatory principles, so that a clear understanding of the principles were presented, and this resource was modeled after the work of Community-Campus Partnerships for Health5. Both resources can be accessed through the DE- CTR/ACCEL website at https://www.de-ctr.org/ community/resources.[3]

INTERNAL FUNDING OPPORTUNITIES

Through DE-CTR/ACCEL there are various funding opportunities including; Big Data Pilot Awards, Pilot Grants, Mentored Research-Development Awards (MRDA), Research Retreats, Shovel Ready Pilot Grants (ShoRe), and ACCEL Community Engaged (ACE) Research Awards. The ACE awards are funded through the CEO component and will be described in more detail below. The intent of all ACCEL awards is to support junior and/or senior investigators in research that generates strong outcomes and partnerships, in order to, obtain further translational research support through external funding sources.

EVENTS

The CEO component along with its community partners has organized an annual conference to engage communities along the continuum of research activities, from planning to implementation through dissemination of research findings. Our programmatic work has utilized community-engaged research (CEnR) and Patient-Centered Outcomes Research principles to develop equitable and meaningful translation across our research communities.[4,5] Nationally recognized speakers, interactive panel discussions and workshops are structured to educate about CEnR and community- based participatory research (CBPR).

In years 2 and 3 of the grant, a small working group within the CEO organized networking lunches. The lunches were topic-centered and organized to create a collaborative learning space for people from the research community to meet with like-minded people from the programmatic or implementation community to produce research.

ACCEL sponsored two "speed-dating" events, an interactive timed round table event developed by our CAC to bring together researchers and our community partners. Researchers move around to tables, hosted by community organizations, and learn about the needs and strengths of the community and organization (versus the "traditional" way is usually that community members visit research posters to listen to the presentation or to ask questions regarding the research being conducted). Overall, this opportunity is for sharing of resources, discussing community research questions, and identifying organizational and research needs for potential collaborations on grant proposals. This type of deliberate networking increases awareness across organizations, which would otherwise remain siloed.

Community Research Needs Assessment. Priority health concerns in Delaware were identified through a research survey distributed to community organization leaders. Currently, this tool is being used by project investigators as a request form to receive project support through the CEO component. The assistance provided through the component includes; project planning, identifying funding opportunities, grant preparation, evaluation, participant recruitment, survey development and many more! The resource can be accessed at Community Research Needs Assessment.[3]

ACCEL Community-Engaged ("ACE") Research Awards.[3] Modeled after the successful Community Engaged Scholars Program (CES-P) at Medical University of South Carolina, the CEO component developed the ACE program. This small grants program funds academic-community research partnership projects. The program requires an academic and community partner and asks this team to participate in a curriculum. The curriculum includes research approach, methods and grant writing, as well as, the "Are We Ready" Tool Kit created by our MUSC partners and available for download from: Are We Ready? A Toolkit for Academic-Community Partnerships in Preparation for Community-Based Participatory Research.[6] This free toolkit is a guide to strengthen academic-community partnerships and to implement successful community-based participatory (CBPR) studies. Through individual assessments and guided team discussions, the toolkit leads the partners to collaboratively identify current strengths and challenges, develop action plans to address any barriers, and create an equitable partnership that will create lasting relationships and impactful interventions.

Recorded lectures, power points and learning materials are available from all three years of the ACE curriculum at CTR website.

Community Forum.[3] An interactive discussion board, launched in April 2016, is available to the general public and was developed to allow for researchers and community partners to pose questions, opportunities, and topics for discussion. The forum can help prompt conversation among our fellow ACCEL investigators and community members with recent or current projects to discuss ways that the projects are impacting the community, or even act as a resource for making connections. The community sub-site3 on the DE- CTR/ACCEL website includes more information about: who we are, resources, funding opportunities and technical assistance.

Moving the Needle/Gap Analysis.[3] In order to effectively "move the needle" on healthcare concerns within the State of Delaware, the CEO component developed a tool to identify current work within the ACCEL program. Shown in Figure 2, the map identifies funded ACCEL research projects across New Castle, Sussex, and Kent counties that align with the health initiatives and Delaware State Innovation Models (SIM) Initiative. The goal is to continue to

fund research while making an impact across the state by eliminating health disparities, and to share the strategies and connections made through funded projects.

Figure 2. Moving the Needle, Public Health Initiatives Across DE
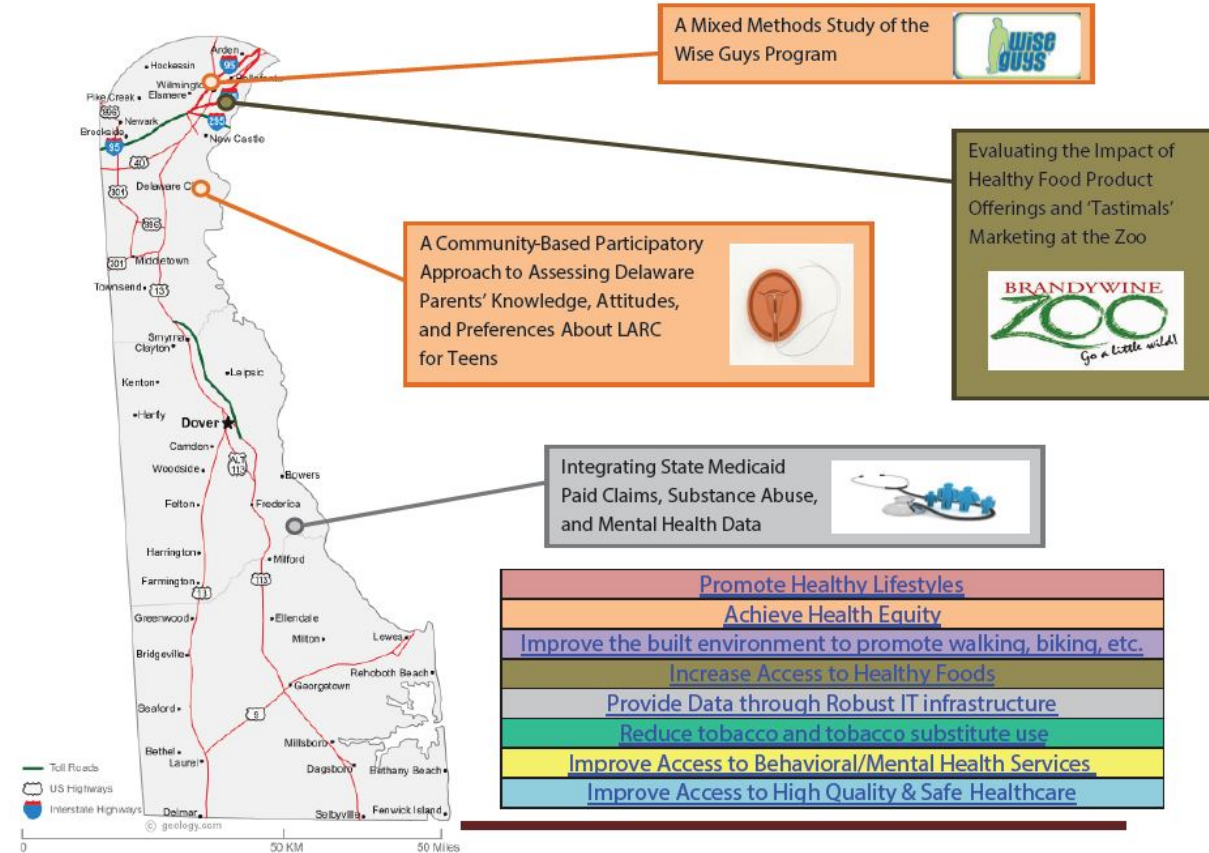
RESULTS

The top strategies used to engage community partners in research within ACCEL are summarized in Table 1. Further outcomes related to all strategies used by the CEO component are reported below.

Table 1. Summary of ACCEL Community Engagement Strategies

Strategy	Description
Community Research Exchange (5/12/14, 5/18/15, 5/23/16) **Reach: 628 participants**	(i) Planning committee consists of leaders and members of ACCEL institutions and CAC members (ii) Large assembly of community members, researchers, health care providers and leaders to discuss health priorities of Delaware (iii) Nationally-recognized keynote speakers present on key theme of conference related to major health concerns in Delaware (iv) Moderated oral and poster presentations from both ACCEL awardees and community-based researchers

	(v) Formal facilitation of workshops around key community-engaged research approaches and health topics
ACCEL funding: Research Retreat (7/6/15) **Reach: 81 participants**	(i) Identify and promote high-impact areas of research and interdisciplinary collaboration (ii) Organization of a formal or informal meeting to promote area and generate ideas and partnerships for potential grant submissions (iii) Recruitment of community members and researchers for participation
Speed-dating events (4/27/16, 9/29/16) **Reach: 81 participants**	(i) Community-based organizations present information around community needs of Delaware (ii) Make connections and build partnerships through a timed session (iii) Researchers discuss interests compared to community needs to generate research or provide research guidance
ACE Awards **Reach: 29 submissions**	(i) Build curriculum and call for proposals around key elements of community-based participatory research (ii) Support online submission process through DE-CTR/ACCEL website (iii) Develop rigorous review process for competitive applicants actively involving community in clinical and translation research priorities (iv) Train academic and community scholars to conduct partnership research that engages the community in the research experience (v) Guide investigators to potential grant opportunities and encourage publications and presentations on research outcomes

Annual Community-Engaged Research Partnership Conference and Workshops. Three CEO Academic Community Research Partnership conferences (5/12/14, 5/18/15, and 5/23/16) were organized with a total reach of 628 participants of which 254 identified themselves from a community-based organization. Several nationally-recognized keynote speakers discussed topics such as "Challenges and Opportunities in Community Engagement for CTR", "Research for Advocacy and Policy Change", and "Partnering with Patients, Practices and Communities in Clinical and Implementation Research", "Community Engagement for Urban Health," and "Healing from Adverse Community Experiences: Public Health Strategies to Prevent/Address Trauma Related Violence." Interactive panel discussions consisting of experts in CBPR,

academic researchers, community members, and healthcare professionals have shared experiences from research projects with community participation.

The conference concludes with facilitated workshops from leaders in Delaware who have presented on; How to write a Community-Engaged Research grant proposal, Data is your friend: How to incorporate evaluation into your research, Rehabilitation Research, Tobacco prevention: From research to policy, Working with the media: How your external affairs group can help, Breastfeeding In the Workplace: A Planning Session for a Grant, Trauma Informed Approach: Organizational Culture, Community Prevention and Patient Care, Participatory Research, and Using "Big Data Strategies" to Address Violence Prevention. With inclusion of all workshops, the total reach is 445 individuals. Visit Community Research Exchange3 to find information regarding the latest conference.

Research retreat. The CEO component was awarded and organized a retreat around a CBPR approach to develop and test a multilevel evidence-based intervention that targets African-American fathers-to- be, with the goal of reducing infant mortality, reducing children's exposure to adverse childhood experiences, and improving child developmental outcomes. To-date one retreat resulted in establishing a working group that submitted one grant proposal.

Speed-dating event. A Community Engagement and Outreach Events Evaluation3 [n=63] captured 21 new connections made during both events which resulted in 1 ACE award project around adverse childhood experiences and 3 established working groups that look to pursue grant opportunities.

ACCEL Community Engaged "ACE" Research Awards.

There were 29 submissions over three years and 10 funded teams. Over 150 people have attended the three kick-off events which were organized to promote awareness of the awardees across the community. The curriculum had 32 participants from the 10 different awardee teams involving 12 different community organizations. The community organizations include; Tobacco Prevention and Control Program at DHSS/DPH, Healthy Delawareans with Disabilities at CDS, Cancer Support Community Delaware, Helen F. Graham Cancer Center, Community Health Outreach & Education, CCHS Center of Excellence in Women's Health, Children and Families First, Charleston Community to Research Action Board, Brandywine Zoo, Endless Possibilities in the Community, the Visiting Nurse Association of Christiana Care, Delaware Guidance Services for Children and Youth, Inc., and HMS School for Children with Cerebral Palsy.

Year 1 awardees completed their 1-year projects in May 2016, Year 2 awardees are more than half-way through their funding period, and Year 3 awardees began in late 2016. Based on progress reporting, outcomes from the first two years are organized in Table 2. In addition to the success of our awardees, the ACE curriculum has been evaluated and adapted accordingly and has been incorporated into our state's first successful Patient- Centered Outcomes Research Institute (PCORI) grant, entitled "Engaging Stakeholders to develop a patient- centered research agenda for chronic kidney disease in Delaware."

Table 2. Summary of ACCEL Community Engagement Outcomes

Type of Accomplishment	Total Outcomes
Awards (Mentoring & Fulbright Scholar, respectively)	2

Local and National Presentations (oral & posters)	17	
Publications	3	
Grant submissions (ACCEL and external)	6	

Moving the Needle/Gap Analysis. Due to early implementation of the interactive document it is too early to report outcomes. The goal is to be able to identify all connections and relationships made through funded DE-CTR/ACCEL awards, and to report information regarding the projects through a three dimensional view. As a viewer, one will be able to essentially understand the story of how the scientific or community-based research project was initiated, understand the investigators involved, access the abstract of the project, learn about findings or outcomes, and most importantly, make the connection on how the project impacted the community of Delaware.

Networking Lunches. A total of 70 individuals were reached including; 59 in-person and 11 remote via video conferencing. Five distinct lunches were organized including topics of nutrition, health equity, adolescent reproductive health, social determinants of health, and infant language development. Outcomes include increased awareness of ACCEL program, current and on-going work across community organizations and ACCEL institutions, and networking connections for potential collaborations on grant submissions.

Community Needs Assessment. Over 30 community partners participated in the community research needs assessment and the CEO was able to consult, as well as, link those partners with the appropriate resources through ACCEL including Epidemiological and Biostatistical support,[3] Pilot Grants Program,[3] and Mentoring, Education, and Career Development.[3]

Principles of Partnership & One Voice. The "One Voice" communication tool kit and Principles of Partnership resources have reached 17 individuals during coalition meetings and using Google Analytics, we were able to identify 56 page views specifically on the resources web path on the DE-CTR website. More utilization of these resources will be marketed through future community engagement and outreach events and committee meetings.

Community forum. A recent development of an interactive discussion board known as the 'community forum' consists of a total of 24 posts that were made on the community forum around 14 different topics addressing the ideas of improving health of Delawareans, identifying communities and community stakeholders, funding opportunities, finding collaborators for research tools, and ways to engage with the CEO through various activities. Further posts will include updates and reporting of outcomes from all funded DE-CTR/ACCEL awards. Prior to the posts, there were concerns on the number of alerts being received by subscribers each time a post was made. Therefore, many test postings were made by the CEO and DE-CTR/ACCEL website team to resolve issues.

In result of the methods mentioned above, as of January 2017, the CEO component currently has 2 active external grants, 3 pending notice of awards for grant submissions, and 2 grants under development or in process. The active grants are a Patient-Centered Outcomes Research Institute (PCORI) utilizing the ACE curriculum and a Chairs Leadership Council at Christiana Care around Informed Decision Making in Lung Cancer Screening. Three manuscripts are currently in-press. A total of 37 presentations including 22 posters and 15 oral were presented both locally and nationally during the first three grant years of the ACCEL program.

CONCLUSION

Community engagement for translational research requires support, resources, inclusion, active planning, and thoughtful approaches for meaningful success.

The DE-CTR/ACCEL program placed appropriate emphasis on the CEO component in its grant application, specific aims, project development, funding, leadership team, and activities. That support for infrastructure and recognition of the importance of community engagement as an essential component of the program enabled the initial success and outcomes described. Outreach must be bidirectional, engaging the community in research, but equally important, engaging the researchers to work with their target communities. We built partnerships around themes which represented research strengths and health priorities for our communities. Relationship building, while not easily quantified by traditional measures, is evidenced by quality and frequency communication, community goals, and genuine value for the role of all partners. Such relationships are the capacity building needed for true sustainability and impact in translational research.

For any translational science grant/research program, continued success relies on demonstrated outcomes, i.e. publications and funding. Assessment of community contributions to that research success, extent of engagement of community members and organizations, and, ultimately, the impact of the partnership research to improve health across the community will be essential to measuring the true outcomes of the engagement process. We are encouraged by our early success in outreach and public funding, and anticipate continued success in these areas, as well as, in our most important measures, improving healthcare outcomes and reducing healthcare disparity in our communities.

DECLARATIONS/ACKNOWLEDGEMENTS

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