

UC San Diego

UC San Diego Previously Published Works

Title

Building Community Engagement Capacity in a Transdisciplinary Population Health Research Consortium.

Permalink

<https://escholarship.org/uc/item/75d1q43v>

Authors

James, Aimee

Nodora, Jesse

Maki, Julia

et al.

Publication Date

2024

DOI

10.54656/jces.v16i2.496

Peer reviewed



HHS Public Access

Author manuscript

J Community Engagem Scholarsh. Author manuscript; available in PMC 2024 July 25.

Published in final edited form as:

J Community Engagem Scholarsh. 2024 ; 16(2): . doi:10.54656/jces.v16i2.496.

Building Community Engagement Capacity in a Transdisciplinary Population Health Research Consortium

Aimee S. James, PhD, MPH,

Division of Public Health Sciences, Washington University in St. Louis School of Medicine, St. Louis, MO.

Jesse Nodora, DrPH,

University of California-San Diego, Department of Family Medicine and Public Health, La Jolla, CA.

Julia Maki, PhD,

Division of Public Health Sciences, Washington University in St. Louis, School of Medicine, St. Louis, MO.

Bernard L Harlow, PhD,

Department of Epidemiology, Boston University School of Public Health, Boston, MA.

Lisa Kane Low,

School of Nursing, Women's Studies, Department of Obstetrics and Gynecology, University of Michigan, Ann Arbor, MI.

Tamera Coyne-Beasley, MD, MPH,

Department of Pediatrics, University of Alabama at Birmingham Heersink School of Medicine, Birmingham, AL.

Shayna D. Cunningham, PhD, MHS,

Department of Public Health Sciences, University of Connecticut School of Medicine, Farmington, CT.

Ayah El-Fahmawi,

Department of Surgery, Division of Urology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA.

Heather Klusaritz, PhD, MSW,

Department of Surgery, Division of Urology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA.

Terri H. Lipman, PhD, CRNP,

Department of Family and Community Health, School of Nursing, University of Pennsylvania, Philadelphia, PA.

Melissa Simon, MD,

Corresponding author: Aimee S. James, PhD, MPH. Division of Public Health Sciences, Department of Surgery, Washington University School of Medicine, St Louis, MO. aimeejames@wustl.edu.

17Division of General Obstetrics and Gynecology, Department of Obstetrics and Gynecology, Northwestern University Feinberg School of Medicine, Chicago, IL.

Jeni Hebert-Beirne, PhD, MPH

Division of Community Health Sciences, University of Illinois at Chicago, School of Public Health, Chicago, IL.

of the Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium

Abstract

Community engagement has been named a research priority by the National Institutes of Health, and scholars are calling for community engagement as an approach to address racism and equity in science. Robust community-engaged research can improve research quality, increase inclusion of traditionally marginalized populations, broaden the impact of findings on real-life situations, and is particularly valuable for underexplored research topics. The goal of this paper is to describe lessons learned and best practices that emerged from community engagement in a multi-institution population health research consortium. We describe how a foundation was laid to enable community-engaged research activities in the consortium, using a staged and stepped process to build and embed multi-level community-engaged research approaches.. We staged our development to facilitate (a) awareness of community engagement among consortium members, (b) the building of solidarity and alliances, and (c) the initiation of long-term engagement to allow for meaningful research translation. Our stepped process involved strategic planning; building momentum; institutionalizing engagement into the consortium infrastructure; and developing, implementing, and evaluating a plan. We moved from informal, one-time community interactions to systematic, formalized, capacity-building reciprocal engagement. We share our speed bumps and troubleshooting that inform our recommendations for other large research consortia—including investing the time it takes to build up community engagement capacity, acknowledging and drawing on strengths of the communities of interest, assuring a strong infrastructure of accountability for community engagement, and grounding the work in anti-racist principles.

Keywords

transdisciplinary; research consortia; antiracism; reciprocity; bladder health; strategic planning

Introduction and Background

The National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) have named community engagement (CE) in research as a priority (Kimmel et al., 2019; NIDDK, 2021; NIDDK, 2023; McCloskey et al., 2011). Calls for CE in research align with the broad call for anti-racist science that recognizes the role research enterprises and researchers have had in consciously and implicitly continuing overt and systemic racism in research framing and practices. (Boyd et al., 2020; Ford et al., 2018; Headen et al., 2022; Jones, 2018; Yonas et al., 2006). Building CE into clinical, translational, and transdisciplinary research is one strategy to conduct responsive and rigorous research grounded in engagement, equity, and anti-racist thinking. Strong and sustained CE can improve the relevance of our research, ensure that we meet the

needs of populations, increase inclusion and consideration of those facing inequities and who are marginalized, and improve credibility and generalizability of findings (Kim et al., 2020). It can also inform and support the success of future dissemination activities. Community-engaged research is particularly valuable in research topics for which less is known scientifically—where lived experience is critical for understanding the challenge—and for many health-promotion endeavors (McCloskey et al., 2011).

Large research consortia are increasingly interested in community-engaged approaches. Yet, it can be challenging and time-consuming for consortiums to integrate and implement CE practices into their research frameworks, activities, and deliverables, particularly if not all investigators are familiar with or comfortable with CE. Community-engaged transdisciplinary research requires building trust among academic investigators from varied disciplines as well as trust between academic and community partners (Alang et al., 2021) to generate new scientific discovery (Barkin et al., 2013). This trust needs to be multi-directional, which can be difficult due to power structures, differential valuing of expertise (between academic and community as well as across disciplines), and the history of racist and discriminatory practices of institutions, research enterprises, and researchers (Coombe et al., 2020; Jagosh et al., 2015; Lucero et al., 2020; Wallerstein et al., 2020).

Research Context

The Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium was launched in 2015 with a mission to conduct research on prevention of lower urinary tract symptoms and promote bladder health among diverse populations of women (Harlow et al., 2018). PLUS is a transdisciplinary consortium that includes research expertise in clinical, public health, and population health across eight clinical sites (i.e., research centers) and a scientific and data coordinating center, all within academic institutions across the United States. A steering committee, with voting members comprised of all principal investigators and the NIDDK project scientist, meets regularly to set research agendas and consortium policies. All investigators and community stakeholders who serve as investigators within PLUS are encouraged to contribute during each steering committee meeting.

An early aim of PLUS was to lay a foundation that brought strategic socio-ecologic and health-equity thinking into how PLUS research was conceived, created, and operationalized, and ensure that resulting research met the concerns of people who identified as women and girls (Brady et al., 2018). Our foundational research endeavor, which has informed our subsequent research, was a robust national qualitative study to gain insight into experiences around bladder functioning and behaviors (Low et al., 2019). Ultimately, PLUS intends to produce scientifically based evidence that informs interventions on multiple socio-ecological levels (societal to individual) to promote bladder health among women and girls. PLUS is in its ninth year of NIH funding.

Although this transdisciplinary approach fosters input from many different disciplines, PLUS on the whole did not have embedded community-engaged principles or processes planned at the very start. Investigators within PLUS with prior CE experiences advocated early on for the value of CE and employing best principles and mechanisms. This expertise

was leveraged within the consortium to encourage a wider embrace of CE to advance the mission of bringing community voices and experience to the center of a research process focused on bladder health.

In this article, we critically examine the PLUS approach to CE and discuss a) how investigators built CE research principles into the consortium infrastructure, b) how this infrastructure was used to integrate CE activities into many aspects of PLUS research and dissemination, and c) the successes and challenges experienced once strategies were applied, and how they were addressed. We offer lessons learned and assert that anti-racist CE is not only possible in such a setting, but essential to rigorous and responsible health-equity study design to ensure that research activity is feasible, inclusive, important, useful, and acceptable to the people at the center of our research aims. Community members were not engaged in research as participants, therefore no ethics approval was required for the activities presented here.

Getting Started: Building CE Infrastructure

At some of our first meetings, many PLUS Research Consortium members recognized the need to engage community members to integrate their expertise into the overarching work of the consortium, and the importance of authentic engagement to improve the impact of our research. There was, however, wide variation in comfort, capacity, and competency in CE across the members of the consortium, reflective of the diversity of experience among the researchers. Not all centers included expertise and experience with CE research at the start, and only one center had included co-investigators from outside academia. With a multi-disciplinary team of researchers, diverse research centers, and varying levels of CE familiarity and capacity, it became clear that we needed to develop a common mission and plan for how community engagement could be integrated into PLUS research. This included establishing shared understandings and a strong foundation in order to advance our CE methodologies and achieve our goals. The CE leaders planned a staged and stepped approach to bolster the role of CE in our research methods, starting with engaging community partners to inform foundational research activities and building a multi-level engagement infrastructure with local and joint components and a common strategic focus. Our approach, outlined below, includes challenges, lessons learned, insights, and a model for other research consortia or multi-center studies.

Methods: A Staged and Stepped Process to Build and Embed Engaged Approaches

Early on, the CE leads realized it was important to proceed carefully to create shared understandings and language, and nurture CE participation and commitment so that we could sustain engagement across all PLUS centers for the duration of the consortium. We **staged** our development to facilitate initial awareness of CE, build solidarity and alliances for trust-building and credibility, and initiate of long-term engagement that would allow for meaningful translation of PLUS research into impact and action. Our process included: (1) *strategic planning* to identify a vision for CE in PLUS and engage key cross-consortium leadership; (2) *building momentum* by addressing awareness, comfort, commitment, and

competencies for engaged research; (3) *embedding processes* that sustained CE into consortium infrastructure through structures, policies, and resource allocation (including additional expertise in CE); (4) *developing, implementing, and evaluating* CE activities across all PLUS research to actualize our vision.

We also used a **stepped** implementation approach that moved from informal and one-time community interactions to systematic, formalized, capacity-building reciprocal engagement. We describe our trajectory in building an infrastructure that formalized and sustained systems for both short- and long-term engagement with diverse community partners.

Step 1: Strategic Planning

Setting a vision.—We started by defining a vision for how CE in PLUS could look and function, anchored in the perspective outlined by the Centers for Disease Control and Prevention (CDC) that the populations affected by research should be invited to actively contribute throughout the entire study process (McCloskey et al., 2011). We sought to achieve an approach to CE that was “fit for purpose,” grounded in the scientific evidence base of CE and also acceptable to the developmental needs of the consortium (O’Mara-Eves et al., 2013). We drew from theoretical underpinnings that posit that engaging those impacted by the phenomena of interest in the investigation and solution generation increases the rigor and relevancy of the work while attending to issues of justice, fairness, and capacity building. We adopted engagement mechanisms that were efficacious and suited our unique developmental and practical needs (Chávez et al., 2008; Chávez et al., 2007; Freire, 1968/2018; Wallerstein & Duran, 2003).

Our vision and strategic plan were co-developed with investigators and research coordinators across centers and from different disciplines through discussion and consensus building. The PLUS Community-Engagement Toolkit was developed and presented to the consortium in year two (2019) and included a CE organizational structure, principles guiding our CE approach, and strategies for research centers to start CE activities. We developed a CE Statement of Value when we introduce the toolkit:

CE Statement of Value: CE is important to all PLUS studies and related dissemination and goals. While research protocols help ensure quality research data, community-engaged review and feedback provide an additional perspective in the research process. CE insight adds relevance and cultural rigor and ensures that research activity is feasible, important, useful, and acceptable to the people our research aims to help and other stakeholders necessary to effect change. A CE review of proposed and ongoing research helps verify and enhance the likelihood that study results and interpretation are grounded in community experience and can ultimately inform bladder health promotion and related public health and medical practice.

Developing clear guiding aims, principles, and a strategic plan.—Meaningful sustained collaborations require clear aims and a deliberate and resourced strategic approach (Ahmed & Palermo, 2010; Anderson et al., 2012). Our multi-tiered CE approach is guided by five aims: (1) PLUS research will be relevant to broad community needs and outcomes; (2) study findings and interpretations will be grounded in community experience and

understanding, and are relevant and credible within community members' experiences; (3) PLUS research centers will have the ability to build public support for research, future action, and intervention, and solicit recommendations from constituent communities; (4) PLUS will identify and cultivate community partners over time who will help enable the consortium to collect high-quality evidence that can inform bladder health promotion and related public health and clinical care; and (5) PLUS will efficiently and effectively disseminate information and findings across clinical, scientific, and community-member audiences. The plan drew from best-practice CE literature and included increasing levels of engagement with a range of activities and representation from different identities and experiences, a CE leadership group, intentional involvement of population- and community-centric investigators across consortium subcommittees, research to build our social infrastructure in the communities we engaged with, and working with research coordinators and site-specific CE specialists (Aday et al., 2015; O'Mara-Eves et al., 2013). Our strategic plan is shown in Figure 1.

Step 2: Building Up—Assess and Grow Comfort, Competency, and Commitment

Building CE in PLUS required examination of whom to engage and how, paired with internal consortium member education to raise awareness of engagement approaches and generate buy-in and support to obtain CE resources.

With our focus on bladder health, we wanted wider engagement than disease- or symptom-focused groups, so we needed to engage broad and strategic representation of people who identify as women or girls. We also knew we would be introducing a kind of academic expertise for which there is implicit bias in the academy, and few models of how to level this power imbalance (Del Pino et al., 2016). After gaining initial buy-in (and resources) during years one and two, the CE leads convened a series of presentations and conversations at all-consortium meetings to establish a shared language and understanding of best practices for community-engaged research. Presentations introduced evidence and strategies for engaging community members across all PLUS research centers. In the early years, CE presentations were a consistent agenda item during all-consortium meetings as continuing education to keep investigators and team members aware of ongoing and planned CE activities.

While not unexpected in a clinical research environment steeped in hierarchy and scarce resources, we needed to address doubts and misconceptions around CE research and its value for the work of the consortium. These interactive discussions encouraged questions, aiming to create a safe space for open conversation and appreciating the learning and adoption curve. The CE team encouraged moving away from unidirectional approaches ('us talking to them') or spotlights on narrow topics (e.g., study recruitment) and toward openness to community input and bidirectional conversation (Hebert-Beirne et al., 2018). These sessions also addressed skepticism around how CE enhances rigor and impact; differences between qualitative research and CE; and inclusion, equity, and representation in CE research. As we progressed, we also addressed hesitancy around incorporating community feedback (particularly when it contrasts with research plans or investigator ideas). At the same time, the CE team was open to learning from colleagues new to CE. This joint learning approach helped us continue to identify areas for improvement. Out of this,

we have built and continue to refine the PLUS Community-Engagement Toolkit; a living document that grows and evolves as our research and engagement continues, and includes policies and processes for CE in PLUS, CE best practices, and CE strategies adapted for PLUS centers.

A critical part of building momentum was the acknowledgement and acceptance that different PLUS research centers had different levels of expertise and capacity for engagement, and that their approaches to engagement would necessarily be adapted to local context, norms, and customs. Our toolkit is designed to work with that adaptation and localization for common goals and questions. All sites used similar strategies and question prompts in their community engagement, but each site adds local flavor and ways of working best with their community members. This valuation of local expertise is a thread throughout all our work and a key to our success.

An early step in building knowledge and experience with CE was to hold informal community conversations. These were designed to align with methodologic and ethical guidelines of consulting communities and provided paths for investigators new to CE to enter into conversations with community members about bladder health and PLUS research (Dickert & Sugarman, 2005; Joosten et al., 2015). Community conversations were generally informal with established or new community partners, beginning with a short presentation about PLUS followed by facilitated discussion about bladder health and research needs. These provided foundational experience and exposure for center investigators at the local level, added perspective on how bladder concerns were experienced, and created the roots of relationships and strategies that would evolve into deeper engagement.

Step 3: Embed CE into Consortium Infrastructure

While we value localization and adaptation of CE approaches across centers, we also recognize the need for coordination and cohesion across our universities to increase organizational capacity and collective synergy toward our common goals (Lasker et al., 2001). We leveraged boundary-spanning theory—in particular, social closeness and task orientation—to embed CE into consortium activities and ensure consistent application (Weerts & Sandmann, 2010). For CE to strengthen all of our consortium research, we needed clear and formal infrastructure and we needed resources to ensure that CE was authentic and followed best practices. This meant difficult conversations about where CE ‘sat’ in our organizational structure and priorities for resource allocation. Ultimately CE grew from a temporary workgroup to a formal and standing subcommittee that is responsible for organizing and implementing engagement and linking with community partners. It is comprised of a transdisciplinary group of PLUS investigators and research coordinators with experience or interest in community-engaged research and has representatives from all research centers. Investigators who identify with and serve specific communities—including the lesbian, gay, bisexual, trans, and queer (LGBTQ) communities and the general community—are also members of the CE subcommittee.

To formalize and mobilize engagement, the founding co-chairs proposed a budget for the resources needed to implement and sustain CE, including salary support for a CE coordinator. Budgetary support for the coordinator and site-specific CE personnel was

approved by the consortium leadership in year two and included in subsequent-year grant budgets. This formal recognition and resource allocation was a critical first step to get centers to hire personnel with protected time dedicated for CE and compensate community partners for their expertise. Over time, this has led centers to bring on additional co-investigators with experience and expertise in community relationships and engagement.

Once capacity was growing, we needed infrastructure so that researchers across the consortium could access and benefit from our strong and growing CE culture. We worked with the coordinating center to develop a RedCap form for researchers to request input from the CE subcommittee or from our partners. This system facilitated the assessment of our CE activities and created a tracking system to know how and when our research initiatives were engaging with community.

Step 4: Develop and Implement CE Activities

Once resources were allocated and structure was outlined, we had to refine and implement our engagement activities (a list of CE mechanisms is shown in Table 1). We had started with community conversations to get informal feedback on general directions, as outlined in Step 1: Strategic Planning. As resources were shifted toward CE, a team of CE specialists (dedicated community-oriented staff at each research center) worked to build and maintain relationships with local community members and stakeholders through additional community conversations (i.e., informal discussions), information sessions (i.e., question-and-answer sessions with health experts); and other collaborative relationship-building events. Partnerships emerged from new and existing relationships with people interested in bladder health. Formal and informal processes (e.g., discussions during meetings, and site surveys such as the Survey of CE Partnerships, examining relationships with key stakeholders at each socio-ecologic level of our PLUS Consortium Conceptual Framework that guided our research (Brady, 2018) assisted in determining the types and strength of connections with various communities at each site, with an eye towards representation across various demographics, life experiences, life course stages, and socio-ecologic levels.

As relationships deepened with community members and stakeholders, and as our engagement progressed, individuals were invited to be Rapid Assessment Partners (RAPs) with whom we collaborated on multiple issues over time (resources were moved from community conversations to support RAPs). When a request was made by PLUS research work groups for community input on research activities, each center's CE specialists coordinated to connect individually or in groups with local RAPs to obtain input and insight into the question at hand. With our emphasis on valuing local knowledge, needs, and practices, we encouraged CE specialists to adapt their approach as appropriate, and allowed for flexibility and adaptation across centers in how this was accomplished. We created feedback loops so that community partners iteratively knew about PLUS activities and saw the results of their contributions. Furthermore, the RedCap tracking database allowed us to organize and maintain records of activities and outcomes. We eventually focused our CE subcommittee work and investigator time into three areas: (1) addressing inclusive recruitment and retention in PLUS research; (2) feasibility and acceptability of planned data collection; and (3) disseminating research findings. Each of these involved bi-

directional communication between investigators and community partners, and also allowed investigators to focus their efforts to continue moving consortium research forward.

Building on the success of community advisory boards as a CE mechanism (James et al., 2011; Matthews et al., 2018), RAPs evolved in to a Community Stakeholder Board (CSB), for long-term engagement. This work is complemented by a Young Women's Health Council (YWHC) that provides ongoing feedback related to our adolescent and young-adult research and capacity-building activities for youth advisors. Moreover, this iterative capacity building also allowed for the development of more participation by community members in the research process; for example, youth participants in the YWHC co-authored a manuscript with PLUS investigators.

Discussion: Creative Problem Solving to Overcome Speedbumps

Multi-disciplinary and transdisciplinary research is known to be challenging. Introducing CE approaches to a group of investigators who are not accustomed to using them is bound to raise challenges and requires trust and patience by all involved. Here we describe some of the challenges we encountered and how they were addressed.

There were varied levels of experience, understanding, expertise, and buy-in across centers and investigators.

While the majority of investigators were enthusiastic about the mission of CE, experience with, commitment to, and/or understanding of CE varied considerably. Some had no CE experience, some had used CE only to encourage recruitment of patients (not community members), and some had experience with community-based participatory action research (widely recognized as a type of community-engaged research that maximizes equal participation from those inside and outside of academia in the research process). Approaches that acknowledge that community members hold expertise and lived experience equal to the academic and clinical expertise of academic investigators can cause discomfort among investigators unfamiliar with CE. This contrasted with the perspective of those already fluent in CE who wanted to move quickly to deeper engagement. Preparing to address inevitable discomfort, the CE team invested time to educate the consortium on the principles, methods, and value of CE, including developing shared understandings of terminology (even across academic disciplines) and best practices. This created joint learning experiences for all involved.

Centers with enthusiasm for CE may not have experience or built-in capacity.

Some centers were enthusiastic, yet still early in building their capacity and skills at CE; other centers did not have funding for investigators or staff with CE expertise on their PLUS team. The lack of built-in resources, expertise, and turnover among CE staff posed challenges that required sites to start slow and build up confidence, capacity, and competence for long-term success. Many sites were only able to hire CE specialists in year three of the program after dedicated CE funding was secured; CE was able to progress more quickly and deeply once that capacity was there. The CE specialists learned from each other and developed tailored CE processes that fit the needs of our research priorities

and diverse communities. We developed and implemented processes to ensure that new consortium members received adequate onboarding to understand the role and resources of CE in the consortium. This is an ongoing commitment as we try to sustain optimal community engagement across all PLUS sites.

For investigators new to CE, we often needed to distinguish qualitative research as a research methodology from CE activities as part of a research approach.

Many of the investigators with CE expertise also had expertise in qualitative research. That, plus a lack of familiarity with CE by some consortium members, led to conflation between qualitative research and CE. For the many PLUS investigators with primarily quantitative research experience, the CE team faced an ongoing need to distinguish between qualitative research activities and CE activities. Relevancy of Institutional Review Board (IRB) considerations helped to distinguish when participants were being engaged to explore research phenomenon and when they were being engaged as thought-partners in the research. There was occasional concern that qualitative methods were not as rigorous or meaningful as quantitative approaches which, when combined with skepticism of CE, added to our challenges. Drawing from lessons learned from other academic-community research partnerships, we deepened our commitment to continued conversation about this distinction and about evidence-based best-practice approaches in all-consortium meetings (Coombe et al., 2020; Holzer & Kass, 2015). Value was bolstered when investigators began to see the benefits and insights gained from both qualitative research and CE.

There was discomfort about reciprocity in the research process.

CE principles involve reciprocity of ‘giving’ to research participants as we ‘take’ their knowledge and expertise. We committed to sharing the changes that resulted from engagement input, and were able to obtain resources to financially compensate partners for their time and contributions. The CE subcommittee was also interested in providing a list of resources for accurate health information and glossary of terms for research participants at the conclusion of their participation, in response to their questions and requests for information. There was concern among some investigators that sharing information on resources would bias the science and/or provide guidance that was not evidence-based. We needed to navigate these new tensions in order to maintain buy-in of community partners, participants, and PLUS investigators. Continued and open dialogue about research practices and assumptions helped us come to shared decisions.

Lessons Learned and Recommendations for Other Consortia

- 1. Acknowledge that CE transforms research processes, culture, and norms.** CE necessitates dedication to the development of and commitment to mutually beneficial partnerships that value the expertise of all collaborators. Pauses to seek out and listen to community partners and the commitment to consider and adapt to community partner input can be areas of discomfort for researchers. Flexibility and adaptation to these partnerships should be embraced but balanced with respect to limitations and benefits.

2. **Plan time for ramp-up and maintenance.** Researchers and funding agencies must acknowledge that trust and engagement takes time, resources, and continued effort. Incorporate a timeline and resources for CE build-up and maintenance. Our community conversation and RAP strategies allowed centers to engage with community members while building the relationships and trust that are key mechanisms in CE (Frerichs et al., 2017). The need for time to build and sustain relationships may hold true even in consortia that planned CE from the start.
3. **Appreciate local expertise and ways of interacting.** We trusted CE specialists and centers to determine the best way to select and implement engagement strategies in their communities, which created different approaches across locations and enriched our learning. Consortia should ground their approach in the core principles of CE research, but allow local expertise and strengths to drive engagement strategies (McCloskey et al., 2011).
4. **Recognize that buy-in, infrastructure, and accountability are necessary for success.** CE is a foundational approach to research, and to anti-racist science from the start. The CE team needs to include investigators with decision-making power (including resource allocation) to support advocacy for CE across the team hierarchy. Ideally, CE should be a requirement as part of the request for proposals and built into proposed research budgets. Such requirements allow faster ramp-up of engagement, sustained commitment to community partners, and the formalization of processes by which community feedback and input is both heard and acted upon.
5. **Evaluate, re-assess, and adapt CE during the research process.** Ongoing evaluation of the effectiveness of CE by community partners and investigators will improve and sustain CE. Consortia can reflect on whether and in what way diverse perspectives are considered in foundational research decisions, approaches, and interpretations. This includes reviewing the diversity in partners and seeing what social-ecological perspectives are missing.
6. **Trust that CE can improve your science, inclusiveness, and rigor.** Foundational to CE research is producing research and results that include those most vulnerable or who are typically excluded (i.e., inclusion as a form of rigor). Our CE approach helped us create approaches and materials that were acceptable, effective, relevant, and inclusive of diverse study participants and communities affected by bladder health issues.
7. **Ground your CE activities in anti-racist principles.** While many research consortia are committed to diversity, equity, and inclusion, CE is a critical strategy for demonstrating such a commitment. Assumptions about representation and inclusion should be discussed and challenged. The opportunity to conduct anti-racist science is enhanced when diverse investigators are included, and when community members are engaged from initiation through dissemination of the research.

Conclusion

Building capacity to sustain community-engaged research within transdisciplinary research consortia requires continuous commitment, ongoing expertise and skill development, and long-term flexibility and learning—similar to any other research methodology. PLUS built a multi-tiered engagement infrastructure with the expectation that our needs would evolve. We progressed from community conversations to RAPs to the establishment of our CSB. We were compelled to intentionally integrate anti-racism to more fully ground our CE in anti-racist practice. We struggled with the implicit bias in the academy that community expertise is not valued for research.

We developed and onboarded new consortium members who were interested or had expertise in CE, advocated for more diversity in investigators, and laid out a long-term goal and the steps needed to succeed. However, orienting new members is an ongoing challenge and need, which is why the infrastructure and formalization of CE within consortium practice is critical to sustaining this approach. When CE is integrated with research protocol development, it is likely to be impactful and sustained, and awareness will be high across consortium members. That said, we had to work within the existing capacities and help grow them, informing the science with CE as we progressed—while at the same time moving toward deeper engagement in the long run. As with many CE efforts, building relationships and trust within the consortium and with community members was essential to solid community engagement and longer-term impact.

Although challenging, with informed effort and a strategic approach, research consortia can effectively incorporate community engagement into their research, infrastructures, and approaches. Building shared languages and flexible approaches can facilitate the engagement across sites that benefits the responsiveness and rigor in our science. The benefit to this work is clear. With a solid CE infrastructure in place for PLUS, we were able to actualize our transdisciplinary research goals of producing evidence to inform the prevention of lower urinary tract symptoms and promoting bladder health equity for all women and girls.

Acknowledgements

We thank colleagues and community partners at participating research centers who participated in the community engagement activities we report on in this manuscript, helped shape our processes and approaches, and taught us much about community engagement and anti-racist practices.

Funding Information

This work was supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) by cooperative agreements (grants U24DK106786, U01DK106853, U01DK106858, U01DK106898, U01DK106893, U01DK106827, U01DK106908, U01DK106892, U01DK126045), with additional funding from the National Institute on Aging and the Office of Research on Women's Health. The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Research Centers and Investigators

Loyola University Chicago: Maywood, IL (U01DK106898)

Multi-Principal Investigators: Linda Brubaker, MD; Elizabeth R. Mueller, MD, MSME

Investigators: Marian Acevedo-Alvarez, MD; Colleen M. Fitzgerald, MD, MS; Cecilia T. Hardacker, MSN, RN, CNL; Jeni Hebert-Beirne, PhD, MPH

Northwestern University: Chicago IL (U01DK126045)

Multi-Principal Investigators: James W. Griffith, PhD; Kimberly Sue Kenton, MD; Melissa Simon, MD, MPH

Investigator: Julia Geynisman-Tan, MD

University of Alabama at Birmingham: Birmingham, AL (U01DK106858)

Principal Investigator: Alayne D. Markland, DO, MSc

Investigators: Tamera Coyne-Beasley, MD, MPH, FAAP, FSAHM; Kathryn L. Burgio, PhD; Cora E. Lewis, MD, MSPH; Camille P. Vaughan, MD, MS; Beverly Rosa Williams, PhD

University of California San Diego: La Jolla, CA (U01DK106827)

Principal Investigator: Emily S. Lukacz, MD

Investigators: Sheila Gahagan, MD, MPH; D. Yvette LaCoursiere, MD, MPH; Jesse Nodora, DrPH

University of Michigan: Ann Arbor, MI (U01DK106893)

Principal Investigator: Janis M. Miller, PhD, APRN, FAAN

Investigator: Lisa Kane Low, PhD, CNM, FACNM, FAAN

University of Minnesota (Scientific and Data Coordinating Center): Minneapolis, MN (U24DK106786)

Multi-Principal Investigators: Gerald McGwin, Jr., MS, PhD; Kyle D. Rudser, PhD

Investigators: Sonya S. Brady, PhD; Haitao Chu, MD, PhD; Cynthia S. Fok, MD, MPH; Bernard L. Harlow, PhD; Peter Scal, PhD; Todd Rockwood, PhD

University of Pennsylvania: Philadelphia, PA (U01DK106892)

Multi-Principal Investigators: Diane K. Newman, DNP; Ariana L. Smith, MD

Investigators: Amanda Berry, MSN, CRNP; Andrea Bilger, MPH; Terri H. Lipman, PhD; Heather Klusaritz, PhD, MSW; Ann E. Stapleton, MD; Jean F. Wyman, PhD

Washington University in St. Louis: Saint Louis, MO (U01DK106853)

Principal Investigator: Siobhan Sutcliffe, PhD, ScM, MHS

Investigators: Aimee S. James, PhD, MPH; Jerry L. Lowder, MD, MSc; Melanie R. Meister, MD, MSCI

Yale University: New Haven, CT (U01DK106908)

Principal Investigator: Leslie M. Rickey, MD, MPH

Investigators: Marie A. Brault, PhD (Dec. 2020–); Deepa R. Camenga, MD, MHS; Shayna D. Cunningham, PhD

Steering Committee Chair: Linda Brubaker, MD, UC San Diego (January 2021–)

NIH Program Office: National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic, and Hematologic Diseases, Bethesda, MD

NIH Project Scientist (at the time of submission?): Julia Barthold, MD

References

- Aday DP, Weeks JK, Sherman CE, Marty RA, & Silverstein RL (2015). Developing conceptual and methodological foundations in community engagement. *Journal of Community Engagement and Scholarship*, 8(1), 15–24. 10.54656/AGEB5515
- Ahmed SM, & Palermo AS (2010). Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health*, 100(8), 1380–1387. 10.2105/AJPH.2009.178137 [PubMed: 20558798]
- Alang S, Batts H, & Letcher A (2021). Interrogating academic hegemony in community-based participatory research to address health inequities. *Journal of Health Services Research & Policy*, 26(3), 215–220. 10.1177/1355819620963501 [PubMed: 33076709]
- Anderson EE, Solomon S, Heitman E, DuBois JM, Fisher CB, Kost RG, Lawless ME, Ramsey C, Jones B, Ammerman A, & Ross LF (2012). Research ethics education for community-engaged research: A review and research agenda. *Journal of Empirical Research on Human Research Ethics*, 7(2), 3–19. 10.1525/jer.2012.7.2.3
- Barkin S, Schlundt D, & Smith P (2013). Community-engaged research perspectives: Then and now. *Academic Pediatrics*, 13(2), 93–97. 10.1016/j.acap.2012.12.006 [PubMed: 23498079]
- Boyd RW, Lindo EG, Weeks LD, & McLemore MR (2020, July). On racism: A new standard for publishing on racial health inequities. *Health Affairs Blog*. 10.1377/forefront.20200630.939347
- Brady SS, Bavendam TG, Berry A, Fok CS, Gahagan S, Goode PS, Hardacker CT, Hebert-Beirne J, Lewis CE, Lewis JB, Low LK, Lowder JL, Palmer MH, Wyman JF, & Lukacz ES (2018). The Prevention of Lower Urinary Tract Symptoms (PLUS) in girls and women: Developing a conceptual framework for a prevention research agenda. *Neurourology and Urodynamics*, 37(8), 2951–2964. 10.1002/nau.23787 [PubMed: 30136299]
- Chávez V, Duran B, Baker QE, Avila M, & Wallerstein N (2008). The dance of race and privilege in CBPR. In Minkler M & Wallerstein N (Eds.), *Community-based participatory research for health: From process to outcomes* (2nd ed.) (pp. 91–106). Jossey-Bass. 10.13140/RG.2.2.20860.95367
- Chávez V, Minkler M, Wallerstein N, & Spencer MS (2007). Community organizing for health and social justice. In Cohen L, Chávez V & Chehimi S (Eds.), *Prevention is primary: Strategies for community well-being* (1st ed.). Wiley.
- Coombe CM, Chandanabhumma PP, Bhardwaj P, Brush BL, Greene-Moton E, Jensen M, Lachance L, Lee SYD, Meisenheimer M, Minkler M, Muhammad M, Rayes AG, Rowe Z, Wilson-Powers E, & Israel BA (2020). A participatory, mixed methods approach to define and measure partnership synergy in long-standing equity-focused CBPR partnerships. *American Journal of Community Psychology*, 66(3–4), 427–438. 10.1002/ajcp.12447 [PubMed: 32744781]
- del Pino HE, Jones L, Forge N, Martins D, Morris D, Wolf K, Baker R, Lucas-Wright AA, Jones A, Richlin L, & Norris KC (2016). Integrating community expertise into the academy: South Los Angeles' community-academic model for partnered research. *Progress in Community Health Partnerships: Research, Education, and Action*, 10(2), 329–338. 10.1353/cpr.2016.0028 [PubMed: 27346780]
- Dickert N, & Sugarman J (2005). Ethical goals of community consultation in research. *American Journal of Public Health*, 95(7), 1123–1127. 10.2105/AJPH.2004.058933 [PubMed: 15983268]
- Ford CL, Takahashi LM, Chandanabhumma PP, Ruiz ME, & Cunningham WE (2018). Anti-racism methods for big data research: Lessons learned from the HIV testing, linkage, & retention in care (HIV TLR) study. *Ethnicity & Disease*, 28(Suppl 1), 261–266. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6092168>
- Freire P (2018). *Pedagogy of the oppressed*. Bloomsbury. (Original work published 1968)
- Frerichs L, Kim M, Dave G, Cheney A, Hassmiller Lich K, Jones J, Young TL, Cene CW, Varma DS, Schaal J, Black A, Striley CW, Vassar S, Sullivan G, Cottler LB, Brown A, Burke JG, & Corbie-Smith G (2017). Stakeholder perspectives on creating and maintaining trust in community-academic research partnerships. *Health Education & Behavior*, 44(1), 182–191. 10.1177/1090198116648291 [PubMed: 27230272]
- Harlow BL, Bavendam TG, Palmer MH, Brubaker L, Burgio KL, Lukacz ES, Miller JM, Mueller ER, Newman DK, Rickey LM, Sutcliffe S, Simons-Morton D (2018). The Prevention of Lower Urinary

Tract Symptoms (PLUS) research consortium: A transdisciplinary approach toward promoting bladder health and preventing lower urinary tract symptoms in women across the life course. *Journal of Women's Health*, 27(3), 283–289. 10.1089/jwh.2017.6566

- Headen IE, Elovitz MA, Battarbee AN, Lo JO, & Debbink MP (2022). Racism and perinatal health inequities research: Where we have been and where we should go. *American Journal of Obstetrics & Gynecology*, 227(4), 560–570. 10.1016/j.ajog.2022.05.033 [PubMed: 35597277]
- Hebert-Beirne J, Felner JK, Kennelly J, Eldeirawi K, Mayer A, Alexander S, Castañeda YD, Castañeda D, Persky VW, Chávez N, & Birman D (2018). Partner development praxis: The use of transformative communication spaces in a community-academic participatory action research effort in a Mexican ethnic enclave in Chicago. *Action Research*, 16(4), 414–436. 10.1177/1476750317695413
- Holzer J, & Kass N (2015). Understanding the supports of and challenges to community engagement in the CTSA. *Clinical and Translational Science*, 8(2), 116–122. 10.1111/cts.12205 [PubMed: 25196710]
- Jagosh J, Bush PL, Salsberg J, Macaulay AC, Greenhalgh T, Wong G, Cargo M, Green LW, Herbert CP, & Pluye P (2015). A realist evaluation of community-based participatory research: Partnership synergy, trust building and related ripple effects. *BMC Public Health*, 15, 725. 10.1186/s12889-015-1949-1 [PubMed: 26223523]
- James S, Arniella G, Bickell NA, Walker W, Robinson V, Taylor B, & Horowitz CR (2011). Community ACTION boards: An innovative model for effective community-academic research partnerships. *Progress in Community Health Partnerships*, 5(4), 399–404. <https://www.ncbi.nlm.nih.gov/pubmed/22616207> [PubMed: 22616207]
- Jones CP (2018). Toward the science and practice of anti-racism: Launching a national campaign against racism. *Ethnicity & Disease*, 28(Suppl 1), 231–234. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6092166> [PubMed: 30116091]
- Joosten YA, Israel TL, Williams NA, Boone LR, Schlundt DG, Mouton CP, Dittus RS, Bernard GR, & Wilkins CH (2015). Community Engagement Studios: A structured approach to obtaining meaningful input from stakeholders to inform research. *Academic Medicine*, 90(12), 1646–1650. 10.1097/ACM.0000000000000794 [PubMed: 26107879]
- Kim MM, Cheney A, Black A, Thorpe RJ Jr., Cene CW, Dave GJ, Schaal J, Vassar S, Ruktanonchai C, Frerichs L, Young T, Jones J, Burke J, Varma D, Striley C, Cottler L, Brown A, Sullivan G, & Corbie-Smith G (2020). Trust in community-engaged research partnerships: A methodological overview of designing a multisite Clinical and Translational Science Awards (CTSA) initiative. *Evaluations & the Health Professions*, 43(3), 180–192. 10.1177/0163278718819719
- Kimmel PL, Jefferson N, Norton JM, & Star RA (2019). How community engagement is enhancing NIDDK research. *Clinical Journal of the American Society of Nephrology*, 14(5), 768–770. 10.2215/CJN.14591218 [PubMed: 30917992]
- Lasker RD, Weiss ES, & Miller R (2001). Partnership synergy: A practical framework for studying and strengthening the collaborative advantage. *The Milbank Quarterly*, 79(2), 179–205. 10.1111/1468-0009.00203 [PubMed: 11439464]
- Low LK, Williams BR, Camenga DR, Hebert-Beirne J, Brady SS, Newman DK, James AS, Hardacker CT, Nodora J, Linke SE, & Burgio KL (2019). Prevention of Lower Urinary Tract Symptoms Research Consortium focus group study of habits, attitudes, realities, and experiences of bladder health. *Journal of Advanced Nursing*, 75(11), 3111–3125. 10.1111/jan.14148
- Lucero JE, Boursaw B, Eder MM, Greene-Moton E, Wallerstein N, & Oetzel JG (2020). Engage for Equity: The role of trust and synergy in community-based participatory research. *Health Education & Behavior*, 47(3), 372–379. 10.1177/1090198120918838 [PubMed: 32437290]
- Matthews AK, Castillo A, Anderson E, Willis M, Choure W, Rak K, & Ruiz R (2018). Ready or not? Observations from a long-standing community engagement advisory board about investigator competencies for community-engaged research. *Journal of Clinical and Translational Science*, 2(3), 129–134. 10.1017/cts.2018.21 [PubMed: 30370064]
- McCloskey DJ, Aguilar-Gaxiola S, Michener JL, Akintobi TH, Bonham A, Cook J, Coyne-Beasley T, Dozier A, Duffy R, Eder MM, Fishman P, Grunbaum JA, Gutter S, Hacker K, Hatcher M, Heurtin-Roberts S, Hornbrook M, Jones S, Lyn M, . . . White-Cooper S (2011). Principles of

community engagement (2nd ed.). NIH NIH publication no. 11–7782. https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). (2021). NIDDK strategic plan for research. NIH publication no. 21-DK-8159. <https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/niddk-strategic-plan-for-research>
- NIDDK. (2023). Pathways to health for all: Health disparities & health equity research recommendations & opportunities. Report of the Working Group of the NIDDK Advisory Council. <https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/pathways-health-all?dkrd=/about-niddk/strategic-plans-reports/health-disparities-equity-working-group>
- O'Mara-Eves A, Brunton G, McDaid D, Oliver S, Kavanagh J, Jamal F, Matosevic T, Harden A, & Thomas J (2013). Community engagement to reduce inequalities in health: A systematic review, meta-analysis and economic analysis. *Public Health Research*, 1(3). 10.3310/phr01040
- Centers for Disease Control and Prevention (CDC). (2011). Principles of community engagement (2nd ed.). NIH publication no. {insert here}. https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf
- Wallerstein N, & Duran B (2003). The conceptual, historical, and practice roots of community based participatory research and related participatory traditions. In Minkler M & Wallerstein N (Eds.), *Community-based participatory research for health* (1st ed.) (pp. 27–52). Jossey-Bass.
- Wallerstein N, Oetzel JG, Sanchez-Youngman S, Boursaw B, Dickson E, Kastelic S, Koegal P, Lucero JE, Magarati M, Ortiz K, Parker M, Peña J, Richmond A, & Duran B (2020). Engage for Equity: A long-term study of community-based participatory research and community-engaged research practices and outcomes. *Health Education & Behavior*, 47(3), 380–390. 10.1177/1090198119897075 [PubMed: 32437293]
- Weerts DJ, & Sandmann LR (2010). Community engagement and boundary-spanning roles at research universities. *The Journal of Higher Education*, 81(6), 632–657. 10.1080/00221546.2010.11779075
- Yonas MA, Jones N, Eng E, Vines AI, Aronson R, Griffith DM, White B, & DuBose M (2006). The art and science of integrating Undoing Racism with CBPR: Challenges of pursuing NIH funding to investigate cancer care and racial equity. *Journal of Urban Health*, 83, 1004–1012. 10.1007/s11524-006-9114-x [PubMed: 17072760]

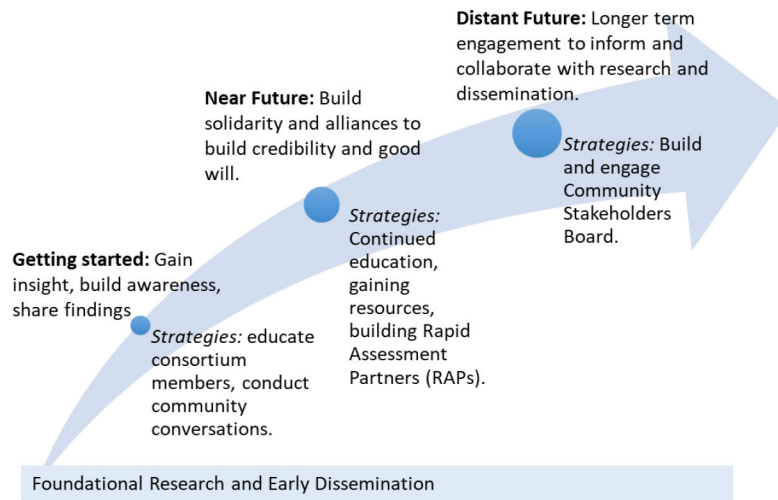


Figure 1. Early Strategic Plan for Community Engagement in the PLUS Consortium.

Table 1

PLUS Community Engagement Mechanisms

Mechanism	Description	Status
Community Conversations	A PLUS event in which community members are gathered for the purpose of bi-directional information sharing without asking participants to review requests or materials or provide feedback. Community conversations are informal.	As needed
Site-Specific CE Specialists	Consortium members, often on a staff level, who serve as a liaison between community members and researchers, providing technical assistance to their site or carrying out CE activities. Site representatives are supported by CE investigators and the CE coordinator.	Ongoing
Rapid Assessment Partners (RAPs)	Community members near each site who are engaged to provide research feedback when requested. RAP participation is fluid and on an 'as needed' basis, building broader community familiarity with PLUS teams. As part of our alignment with anti-racist science, which recognizes race and other identities as social constructs, we avoid the formal collection of metrics of social identity but we purposively recruit participants with an eye to diversity of social context and experience.	Ongoing
Community Stakeholder Board (CSB)	A board comprised of two community member representatives from each of the sites that will inform long-term research agendas and further advance the translation of PLUS research into community-based interventions. The CSB meets twice yearly and was identified in our strategic plan as the outcome of RAPs and early engagement.	Just formed
Young Women's Health Council (YWHC)	The YWHC is a youth advisory board comprised of members aged 14–22 who represent diverse regional and ethnic backgrounds. The group meets virtually on a bi-monthly basis. Meeting agendas are co-created with youth members and PLUS members; time is split between capacity-building activities and discussions to support ongoing PLUS research activities. The YWHC emerged as an engagement activity due to consortium needs.	Ongoing