

Institutionalizing Community-Engaged Translational Science in an Academic Institution: A Community Stakeholder-Driven Process

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ABSTRACT

Background. Although studies have described the power imbalance in academic-community partnerships, little has been published describing how CBPR-informed practitioners can change academic institutions to promote more effective community-engaged research.

Objectives. This paper describes a university-funded community-based participatory project in which academic researchers and their community partners worked together to articulate, develop and advocate for institutionalizing best practices for equitable partnerships throughout the university.

Methods. Findings derive from a collaborative ethnographic process evaluation.

Results. The study describes the integral steps proposed to promote equitable community-university research collaboration, the process by which these principles and best practice recommendations were developed, and the institutional change outcomes of this process.

Conclusions. When universities make even small investments toward promoting and nurturing community-engaged research, the quality of the science can be enhanced to advance health equity and community-university relationships can improve, particularly if based on trust, mutual respect, and openness to accomplish a shared vision.

KEYWORDS: Community health partnerships, Community health research, Health disparities, Power sharing, Process issues, Program Evaluation, Vulnerable Populations

Introduction

Medical research institutions have a fraught relationship with communities of color¹. Unethical treatment of research participants from vulnerable populations have resulted in these communities distrusting the research enterprise^{2,3}. These misgivings are compounded when investigators lack institutional training and support in the principles and best practices of community engagement and social equity^{4,5}. Nonetheless, it is essential that communities of color and other marginalized populations participate in health research to develop and evaluate interventions that meet their health needs⁶⁻⁸.

As community-based practitioners employ research to generate knowledge and contribute to change within complex societies, academic researchers must navigate structural features of universities that create significant barriers for implementing community-engaged research (CEnR), stymie the career progression of academic researchers doing CEnR and CBPR, and discourage research trainees from community engagement. Ensuring that authentic and sustained community-engaged research is institutionalized and its mutual benefits fully realized requires buy-in from individuals in positions of institutional leadership.^{9,10}

Although studies have described the power imbalance in academic-community partnerships¹¹, little has been published describing how CBPR-informed practitioners can change academic institutions to promote more effective CEnR. This paper describes how one partnership catalyzed academic institutional change through a combination of community leadership and academic readiness. The conditions and activities that enabled the partnership to extend the original project goal of increasing recruitment of racial/ethnic minority participants in online studies, to recognizing and advocating for major

institutional changes, show the power of CBPR principles and methods to catalyze transformational changes within research institutions.

Setting

The University. The University of California San Francisco (UCSF) is ranked the top public institution and the second overall in obtaining NIH funding.¹² It was among the first to obtain a Clinical and Translational Science Award (CTSA) in 2006, leading to the establishment of the Clinical and Translational Science Institute (CTSI), including a Community Engagement and Health Policy (CEHP) program. Recognizing the need for community engagement in education and clinical care, the University established the Center for Community Engagement (CCE). CCE and CEHP support CEnR and CBPR practice through consultations between faculty and community partners, teaching research trainees about CEnR and CBPR, and catalyzing the formation of citywide multisectoral health improvement partnerships.¹³

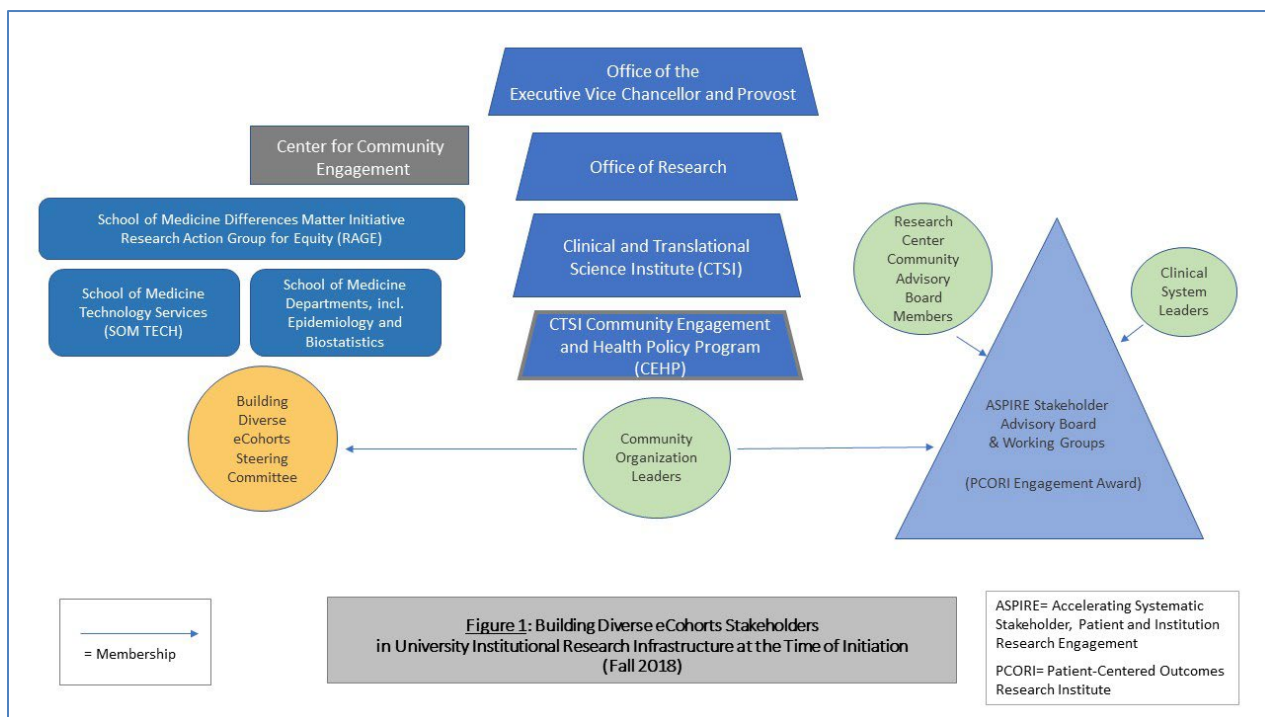


Figure 1. Building Diverse Cohorts Stakeholders in University Institutional Research Infrastructure at the Time of Initiation (Fall 2018)

Origins of Diverse eCohorts. Most health research studies lack participant diversity. Online recruitment and intervention technologies can yield large numbers of participants, but these studies tend to lack diversity, due to the same structural barriers as other studies, and to the digital divide and disparities in technological literacy.¹⁴ For example, the UCSF-based Health eHeart Study cohort consisted of 160,000 web portal-recruited participants contributing patient-reported outcomes through online surveys and data from wearable sensors, smartphone apps, and electronic health record integration. Yet participants were less diverse than those participating in the National Health and Nutrition Examination Survey¹⁵.

Leading UCSF researchers, including a Health eHeart Principal Investigator (Mark Pletcher), obtained internal funding to diversify eCohort studies through a project called

Supporting Diverse E-Cohorts at the University with Technology and Community Engagement (DeC). Originally, DeC's purpose was to assemble diverse community partners as an advisory body to: 1) review proposals submitted by the UCSF eCohorts research projects; 2) select two projects for consultation; and 3) assist with participant recruitment. DeC lasted from June 2018 to December 2019.

The DeC Steering Committee

The Steering Committee constituted the project's principal decision-making body. Comprising approximately twelve people, the Committee met monthly to discuss and resolve issues, develop project deliverables, and strategize about initiatives to sustain the partnership once the funding had ended. The UCSF Committee members consisted of the project PIs, and staff from CTSI's Research Technology Program, the School of Medicine's Technology Services, and CTSI CEHP.

{Insert Table 1 about here}.

Community members included representatives from four San Francisco-based, minority-serving organizations: Central American Resource Center (CARECEN-SF); Chinese Community Health Resource Center; Instituto Familiar de la Raza; and the Rafiki Coalition. Unlike many community-researcher collaborations, most of the community partners held doctoral degrees and were familiar with study design and the institutional culture of academic settings. These members were compensated for their time. Several Committee members, including an academic and community partner and the Staff Manager, also led Accelerating Systematic Stakeholder, Patient, and Institution Research Engagement (ASPIRE), a patient and community engaged research infrastructure-building initiative (Figure 1).

DeC's original charge was to select two e-Cohort studies and help diversify their participants. While establishing the criteria for selecting the studies and understanding their recruitment barriers, the community leaders initiated the discussion of institutional transformation beyond providing effective project consultation and support. This shift in emphasis occurred partially out of necessity, since upgrades to the software platform that would serve as the eCohorts pilot studies' portal were substantially delayed. The community leaders used this delay to develop a strategy for institutional transformation, which was initially a secondary eCohorts goal. We documented the DeC process through an ethnographic evaluation initiated by the community partners and funded equally by a community partner and UCSF. This case study documents the DeC Steering Committee's activities, the process of transforming the original goals and objectives of DeC, and their assessment of the necessary ingredients for developing equitable partnerships among community members, academic researchers, and research institutions.

Methods

We utilized an ethnographic approach, in which the interactions, activities, and perspectives of DeC participants were documented and analyzed. The evaluation consisted of: 1) document review of relevant emails, agendas, meeting minutes and notes; 2) extensive field notes taken during the project's monthly meetings; 3) Semi-structured interviews (n=22) with: a) University personnel directly involved in the project's development and facilitation (n=2); b) Representatives from the participating community-based organizations (n=6); and 3) Researchers from the two DeC-funded projects (n=7). UCSF personnel and community representatives were interviewed at the beginning and end

of the project; we interviewed the funded researchers once. The ethnographer (Michael Duke) coded the data in consultation with the committee members and analyzed it via Atlas.ti, using a thematic analysis approach. In keeping with the project's collaborative ethos, the community experts requested additional, fine-grained analyses and group discussion of the data, to ensure that we sufficiently accounted for the collaborative relationship's development, and the challenges in sustaining that relationship. The research protocol was reviewed by the University of California, San Francisco's Institutional Review Board.

Results

The resulting themes correspond with the literature on CBPR, including rapport-building, trust, respect, open communication, receptiveness to learn and change, balanced power dynamics, and shared decision-making. These group processes and characteristics enhanced the project's original goals into objectives that strove to institutionalize these elements. Below we highlight the five major themes contributing to the transformation of the original project goals and objectives into the transformative goals, objectives and statements of mission and vision. Supporting quotes for each theme can be found in Table 2.

Theme 1. Rapport-Building

Although most of the community partners had enjoyed positive relationships with CEHP staff or the research studies' PIs, their initial interactions with the broader UCSF research community were mixed. Some expressed frustration that research partners had not

taken their suggestions or concerns seriously, or that their participation was merely to demonstrate community engagement in the project.

These experiences posed a potential barrier to developing positive relationships with UCSF researchers and for these partners to fully engage with the DeC research projects. Additionally, not all of the DeC community representatives had worked together previously, nor had many of the University members collaborated substantively in the past. The project's initial meetings reflected the divisions between community members and academics, with the community members and UCSF personnel sitting literally on different sides of the table. Likewise, when Committee members made comments or suggestions, they did so cautiously, to gauge how their remarks might be interpreted.

The Committee subsequently incorporated rapport-building activities into these meetings. CTSI CEHP staff particularly saw their role as fostering a welcoming and respectful environment during these initial meetings, working collaboratively to develop detailed scopes of work for community representatives and clarifying the academic institution's administrative responsibilities. CEHP staff also ensured that community and academic partners co-created agendas, deliverables, and metrics, and that all Committee members vetted collaboratively produced materials. CEHP staff encouraged the community members to take the lead in developing protocols to build rapport and foster appreciation for everyone's expertise. For example, before most meetings participants offered a statement of gratitude when introducing themselves.

The initial meetings took place at UCSF; locations were subsequently rotated to ensure that each community organization hosted the meeting. Having the community organizations serve as hosts contributed to cultural humility and rapport-building,

providing everyone with a more immediate understanding of each organization's mission, cultural practices, and the populations they serve. Meetings were organized around meals, which were funded through the University's budget.

These respect- and rapport-building efforts paid important dividends when Committee members engaged in sometimes uncomfortable discussions around privilege and the hierarchical position of academic researchers relative to community members. In one meeting a tense discussion developed around issues of authorship for DeC deliverables, with the community partners insisting that their intellectual contributions to the project be reflected in the order in which their names appear on these documents. Community partners advocated that prominent authorship status (e.g., first or senior author) should be based on partnership roles, contrary to traditional academic practice. Thanks to the close bonds that had developed among Committee members and a shared set of articulated values that had been reinforced over time, these issues were resolved amicably.

Theme 2. Receptiveness to Learn and Change

From the start, community and academic partners expressed a desire to learn from each other. These principals were incorporated into project meeting agendas, which included time to discuss research methodologies and community perspectives on relevant issues. Without the attitude of receptiveness to learning, and the humility to embrace practical suggestions, institutional changes to the research practices would have been difficult. Committee members also stressed the importance of documenting the content and interpersonal dynamics that facilitated shared learning.

Theme 3. Open Communication

The partners felt that their relationships facilitated open communication on challenging topics, providing members with the space to identify challenges and pitfalls, and to develop appropriate solutions. Respect for each partner's expertise and perspective on balancing what the partners invest and what they should receive in return, further empowered the expansion of the project's initial goals. The established precedent of open communication helped the community partners feel comfortable voicing their concerns, rather than being intimidated by the academic partners, as reported in previous studies^{16,17}. For example, UCSF's accounting system was poorly equipped to provide reimbursement to collaborators like the partners, who are housed in small non-profit organizations. The partners emphasized that these payment delays had a substantial negative impact on their organization's modest budgets. Resulting from this frank conversation, the university staff prioritized tracking down and releasing the payments.

Theme 4. Utilizing the Opportunity to Make a Greater Impact

The community partners took the initiative to transform the original DeC project aims and goals into a more ambitious statement of mission, vision, goals, and objectives in order to make a greater impact on UCSF's research infrastructure. Although developing a statement of common principles was not included in DeC's original scope of work, the Committee dedicated considerable time and effort to drafting the document. With CEHP staff support, the partners formed a subcommittee to draft the DeC mission, vision, and goals statement. Over four months, the full Committee modified and revised these materials during its monthly meetings. Developing these materials would ensure that all the key partners shared a vision of the project that was ambitious and transformative. The final vision statement

clearly reflects this ambition: “(To) transform (UCSF) through deep community partnerships into a model research institution that champions diversity, equity, and inclusion at all levels of health and well-being for the Bay Area community and beyond.”

These goals ran the gamut, from objectives pertaining to the project’s collaborative efforts (e.g., “Sustain the partnership to achieve our mission”) to those that are transformative (e.g., “Learn from and document the process for de-colonizing research and community-academic partnerships”). {Insert Table 3 about here}. The community partners recognized the importance of documenting the process of achieving those objectives, and in assessing whether these goals were being met. A community partner insisted on including an ethnographic process evaluation to document the project’s progress, even though it was not budgeted for in the original proposal, proposing that their organization would provide half of the funding.

The Steering Committee invited UCSF’s senior leaders to attend the meeting where the ethnographic report was presented, to hear the voices of the community members, and to build understanding and buy-in. The resulting discussions were translated into action because of the humility and receptiveness of the steering committee’s academic partners, who believed in CBPR practices and embraced practical suggestions and changes.

Theme 5. Developing Best Practices for Community-Engaged Research

Because committee members held similar perspectives on the importance of researcher-community collaborations, they focused on developing best practices for CBPR research within medical academic institutions, including the University (e.g., promoting equitable partnerships, facilitating capacity-building and co-learning). UCSF’s committee members considered community engagement to be critical for ensuring diverse

participation in research studies, and for gaining a clearer understanding of how particular marginalized populations conceptualize, experience, and address specific health concerns. The community partners, in turn, viewed research collaborations as valuable for identifying and addressing health problems in their respective communities and, when carried out in an equal partnership, serving as a forum for mutual learning and social equity.

To facilitate UCSF's transformation into an institution whose research activities are informed by best practices for community-engaged research, the academic partners acknowledged that the community partners view them as positioned to make change, while respecting the community partners' passion to develop a transformative agenda. University buy-in for advancing institutional change was facilitated by at least three factors: 1) the initial DeC application requesting UCSF funding specifically identified the institutional priority of increasing diversity; 2) two of the co-authors (Mark Pletcher and Tung Nguyen) were long-standing CTSI faculty, increasing the potential for funding sustainability beyond the original grant; 3) university staff held deep expertise regarding funding and infrastructural issues, and maintained ongoing relationships with community partners.

Advancing Institutional Change for Community Engagement

Catalyzed by the DeC Steering Committee's work, UCSF instituted major institutional changes which will, if sustained, support and promote research guided by CBPR principles. (See figure 2.)

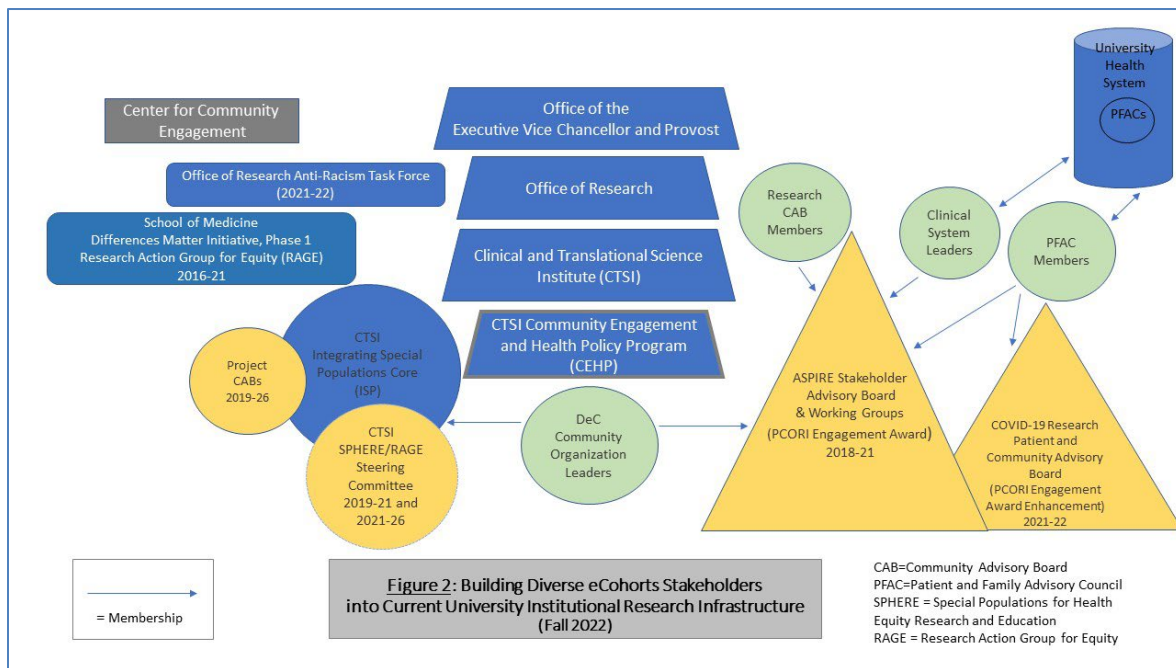


Figure 2: Building Diverse eCohorts Stakeholders into Current University Institutional Research Infrastructure (Fall 2022)

Special Populations for Health Equity in Research and Education (SPHERE). The DeC Steering Committee became the SPHERE Steering Committee, an integral part of the University CTSI’s Integrating Special Populations Core, which aims to increase diverse participation in research for clinical and translational research studies. SPHERE serves as the Community Advisory Board for several large UCSF-based research programs.

CTSI Integrating Special Populations Core. The DeC Steering Committee was also integrated into the CTSI renewal application, which was funded in 2021. The initiative, now called the CTSI Integrating Special Populations Core, is charged with facilitating and increasing research participation of racial/ethnic minorities, particularly in pediatric and geriatric populations. The DeC community organizations are represented in this Core’s Steering Committee, now named the Research Action Group for Equity (RAGE).

Accelerating Systematic Stakeholder, Patient, and Institution Research

Engagement (ASPIRE). Funded by the Patient Centered Outcomes Research Institute (PCORI) and led by members of the DeC Steering Committee, ASPIRE has conducted further needs assessment and asset mapping of UCSF's capacity for CBPR-guided research to achieve health equity¹⁸. ASPIRE recommendations have been used in developing the School of Medicine's strategic planning for clinical research. Its recommendation for truth and reconciliation work as a fundamental step to address research racism and inequities has been adopted by UCSF's research leadership. ASPIRE also created a University COVID-19 Research Patient and Community Advisory Board to ensure sufficient representation of racial/ethnic minorities in such research studies, and that research is conducted ethically to address health inequities.

Conclusion

The DeC project was originally conceived as a program for community organizations to provide outreach, digital design and logistical support to community-engaged projects to facilitate their electronic data collection efforts. However, driven largely by the efforts of the community partners, the project developed a roadmap for university-community partnerships through an iterative process of articulating the project's mission, vision, goals and objectives. The project ultimately aimed to serve as a catalyst for UCSF's transformation, and its relationship to the communities in which it is embedded. Specifically, the Steering Committee utilized the forum to contemplate strategies for developing best practices around institutionalizing CBPR principles and practices at the University and elsewhere. These practices include providing training, mentorship, and institutional support for faculty wishing to develop community-engaged studies^{9,10}. It also

entails elevating the status of community partners within academic institutions, ensuring that they are adequately compensated for their expertise, and that researchers and community organizations seek out opportunities to ensure that the relationships they develop are sustained ^{4,5}.

Despite modest funding, DeC has had an outsized impact on UCSF and its relationship to the San Francisco Bay Area's diverse communities, as evidenced by the Steering Committee's active role in the ASPIRE, SPHERE, and the CTSI Integrating Special Populations core. These markers of success indicate that when universities make even small investments toward promoting community-engaged research and nurturing equitable partnerships with community leaders and organizations, community-university relationships improve, and the quality of the science to advance health equity is enhanced. As the DeC project demonstrates, the key ingredient in ensuring the success of these efforts is making sure that all partners are invested in cultivating an environment of trust, mutual respect, and openness to accomplish a shared vision.

While funding projects to increase diversity among research participants is necessary, it is insufficient to achieve better health and health equity outcomes: such projects are often transactional and focus on easily quantifiable, though largely unsustainable changes. Capacity building and system change are needed for health equity. Partnerships between empowered community leaders, academic research teams, and funders who prioritize capacity building and flexibility as well as project outcomes can lead to institutional changes that promote sustainable health and health equity among diverse populations.

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Table 1. Community and UCSF-Affiliated Organizations Represented by the Diverse eCohorts Steering Committee

Community	UCSF
Central American Resource Center (CARECEN-SF)	Clinical and Translational Science Institute (CTSI)
Chinese Community Health Resource Center	- Community Engagement and Health Policy (CEHP)
Instituto Familiar de la Raza	- Research Technology Program
Rafiki Coalition	School of Medicine
	- Technology Services

Table 2. Themes Contributing to the Enhancement of the Initial Project Goals and Objectives

Theme 1. Rapport Building
“Initially, there was some hesitation, just to be like, ‘Okay, let’s see where this is going’ ... and I was pleased over the year to be able to build a relationship with all of them, and kind of understand where they’re coming from”. – Community partner 1
Theme 2. Receptiveness to Learn and Change
“We do learn from each other and the environment that we attend meetings and scientific panels, presentations It stimulates. It encourages me to learn more and to ask more questions, and ‘How do you ask that question so that you will have a clear answer?’”. – Community partner 2
“Sometimes we lose perspective on that ambition (to institutionalize community-researcher partnerships), so we aim high and push ourselves hard and sometimes it takes that outside perspective to know where we stand relative to other efforts going on in this line of work. So, I’m very grateful that our community partners were so insistent about the evaluation and the publication and getting the word out”. - UCSF partner 1
Theme 3. Open Communication
“One of the reasons that we have a very good relationship with all the academic partners that we work with is because I understand where both parties come from, and how we can achieve a win/win situation. It’s not just for the community or just for the academics. How can we have a win/win partnership?... If you don’t have a win/win partnership, the partnership is not going to last.”- Community partner 3
Theme 4. Utilizing the Opportunity to Make a Greater Impact
“Because it’s like, what is our understanding? Are we on the same page with what our final goal is? And I think the community is very clear, because it’s been screwed over so many times that we need to be very clear and articulate what our expectations are and what we want, because the university for too long has said what they want but hasn’t been reciprocal in delivering for communities... Institutionally things have to shift to work within the community the way the community lives”. – Community partner 4
Theme 5. Developing Best Practices for Community-Engaged Research
“What I see in my value there is really to help and to facilitate what a true community engagement or partnership is. And to really help (UCSF) to go take a step further, not just to finish this project and be done with it, but to take it to a much higher level”. - Community partner 3
“It’s embedded in a goal that we have, and I think many organizations share this goal, which is to reform larger institutions, shift the power balance, the dynamics of who makes decisions when and how, and how our people are seen in the context of those various efforts. We don’t do research, right? But we know research is done on us”. - Community partner 5
“What I really admire most about our community partners is their dedication and their passion for this work, as well as the pride in having a platform about some of this. And with people who have a different level of authority listening and saying, ‘What you’re

saying matters and we want to change the way this works because of your experience”’. -
UCSF partner 2

Table 3- Initial and Enhanced Project Goals

Initial Project Goals
Select and launch two research projects that are acceptable to the community partners and research teams
Achieve the goals of our mission statement while maintaining values. Balance timing needs between UCSF and CBOs
Sustain the partnership to achieve our mission
The timing, scope and scale are appropriate for all parties
Enhanced Project Mission, Vision, and Goals
Mission: The University is the champion for best practices in conducting community-engaged research. The benchmarks for best practices should ensure community participation in all phases of research planning including pre-proposal planning, budget and scope of work development and dissemination of findings.
Vision: To transform UCSF through deep community partnerships into a model research institution that champions diversity, equity, and inclusion at all levels of health and well-being for the Bay Area community and beyond.
Enhanced Diverse eCohorts Project Goals
● Recruitment exceeds expectations, including from communities of interest
● Reduce the digital divide
● Our work results in a large grant to fund future collaborations
● Sustained partnership that achieves our mission beyond the project
● Create a template to institutionalize successful and fundable University-community partnerships
● Through evaluation research, learn from and document the process for decolonizing research and community-academic partnerships
● Findings from the ethnographic study launched by the project are utilized by the community organizations and the UCSF team
Goals for Institutionalizing CBPR Principles at UCSF
● Institutionalize the guiding principles of CBPR for all UCSF research departments, and ultimately all academic institutions. This practice esteems equal community partnership, compensates community partners appropriately, and empowers and builds capacity of the community in conducting research.
● Translate study findings into interventions and policies that benefit the relevant communities
● Build trust with community partners, because the community partners do not want to be “window dressings” for academic institutions
● Determine best practices to support the next generation of minority health researchers and expand capacity of ethnic health practitioners