STAKEHOLDER-ENGAGED RESEARCH FOR HEALTH EQUITY:
FINAL RECOMMENDATIONS TO IMPROVE PROCESSES AND STRUCTURES AT UCSF

Accelerating Systematic Stakeholder Patient and Institution Research Engagement (ASPIRE)
May 5, 2021

In order to address key UCSF research priority areas such as patient and community engagement, health equity and anti-racism, stakeholder engagement is necessary. The Accelerating Systematic Stakeholder Patient and Institution Research Engagement (ASPIRE) project is an effort to improve structures and processes for stakeholder-engaged research at UCSF. Funded by the Patient-Centered Outcomes Research Institute (PCORI), ASPIRE was led by members of the UCSF School of Medicine’s Differences Matter Initiative, the UCSF Center for Community Engagement, the Community Engagement and Health Policy program and the San Francisco Bay Collaborative Research Network of the UCSF Clinical and Translational Sciences Institute (CTSI), the UCSF Research Development Office, and the UCSF Helen Diller Family Comprehensive Cancer Center Office of Community Engagement. ASPIRE was guided by an Advisory Board that included UCSF institutional leaders, community organization leaders, UCSF research faculty and staff, and patient advocates.

Over the course of two years, ASPIRE conducted surveys with 31 PCOR researchers and 14 patient community leaders as well as focus groups with 18 PCOR researchers and 7 patients/community members to explore successes, challenges, and resources needed to advance stakeholder-engaged research. ASPIRE conducted a symposium on October 10th, 2019 titled, “With, By and For the People: The UCSF ASPIRE Symposium on Patient, Community and Stakeholder-Engaged Research at UCSF,” and a second symposium on November 10th, 2020, titled “Stakeholders & Structures: UCSF Research During COVID and Racism Pandemics.” During the first symposium, we presented findings from the surveys and focus groups to the participants before they made their recommendations. The two symposia brought together a total of 250 participants, approximately one-third of whom were patients or community stakeholders, to elicit their input on what UCSF can do to address patient and community engagement, health equity and anti-racism in research.

The recommendations to UCSF leadership outlined here have been provided by the participants from all activities and events, including members of the ASPIRE Advisory Board. The top line recommendations are those made by attendees at both symposia:

- Invest in sustainable community engagement by creating a dedicated, sufficient, and sustained funding base for diverse community engagement at UCSF.
  - A specific example of this would be a “community engagement” allocation on philanthropic gifts and other sources of institutional funds.
- Commit to, promote, and support community partnerships by treating them as building long-term relationships rather than transactional projects. UCSF should enter into equitable partnerships to meet community-identified needs and leverage the resources of UCSF to meet those needs before asking for community support for UCSF’s agenda.
- Create a Community Faculty designation for community research partner leaders as a way to recognize and reward their expertise and contribution and enhance their ability to teach and mentor our research trainees.
- **Establish** and **support** a "matchmaking" platform where community members and organizations can connect with researchers and research groups to work on topics of interest.
- **Challenge** the traditional approaches to "incentives" for research participants by instituting fair compensation for research participation as advisors or participants.
- **Challenge** the traditional metrics of academic success and promotion such as grants, publications, and individual honors and incorporate more socially relevant outcomes such as community engagement, community impact, and health equity.
- **Increase** the number and proportion of Black American researchers and other researchers of color at UCSF, with strategies for retention and advancement.

Additional recommendations from more than one of the sources listed above include:

- **Address** and **challenge** notions of white privilege and white supremacy in all aspects of education and research.
- **Create** a restorative process for transparency, truth and reconciliation to acknowledge past mistakes and past and present harms of research.
- Research leadership should be **collaborative** and **respectful** of community expertise, and power should be shared with diverse community stakeholders.
- **Create** and **support** infrastructure for research capacity and skill building for community partners.
- **Build** and **support** bidirectional communication channels between communities and the university to elicit community input on research priorities and support cross-promotion of events and resources.
- **Make** community representation with adequate compensation on research projects mandatory and provide the infrastructure support required so that this is available for researchers.
  - Support infrastructure to maintain patient and community advisory boards to support and involve community at all stages of the research process from conception to dissemination.
  - Require early community engagement in research projects.
    - Provide pilot funding for researchers to work with community partners early in research process to ensure that research directly addresses community needs and that information generated can be translated into real social impact
    - Encourage researchers to have community leadership in research projects, including as co-principal investigators
- **Train** researchers at all levels to do better in understanding prior research with similar or different topics in communities to avoid unnecessary duplication and in general principles, best practices, available resources for patient and community engagement in research to avoid having the same community input being given over and over again to individual researchers.
- **Increase** diversity among clinical research coordinators and research assistants or associates, and include them as leaders in the research.
Full List of ASPIRE Recommendations

Key:
Prioritized at both Symposia = **Bold**
Prioritized at one Symposium = *Italics*
Recommended by Focus Group Participants = asterisk *
Recommended by Survey Participants = plus +

**Principles UCSF Should Adopt to Address Health Inequities and Racism in Research**

- **Invest in sustainable community engagement, which includes community participation and oversight in research ("Nothing about us without us.")**
  - Examples:
    - Consider community engagement “allocation” from philanthropic gifts to UCSF
    - Prioritization of community engagement funding as a line item
  - *Create a restorative process for transparency, truth and reconciliation to acknowledge past mistakes and past and present harms of research. Learn why communities may be afraid of research.*

- Research should identify and mobilize community strengths and protective factors rather than focusing solely on problems and deficits.

- Understand and incorporate intersectionality. Each person has many identities and should not be limited by one, including ability, age, sexuality, education, class, race, country of origin, housed/unhoused, religion, gender, immigration documentation status and others.

- Leadership in research should be collaborative and power should be shared with community stakeholders. Value stakeholders for their expertise. Shift the balance of power to support BIPOC leadership in research.***

- **Address and challenge notions of white privilege and white supremacy in all aspects of education and research**
  - Example: Change the norm in clinical research that “whites” are the default comparison group, or that research with mostly white participants is more generalizable than research with mostly diverse participants

  - Example: Address underlying issue of funders/funding teams/review committees which are primarily white, as the underlying white privilege leads to values, priorities, funding opportunities, and funding decisions that sustain and promote systemic racism

- Equity should be a priority or the lens through which all decisions are made by UCSF leaders

- Invest in research on racism and racist structures in our academic health center context

- Invest in longstanding relationships to do this well

- Research should identify the structural barriers that result in health problems and inequities in communities

- Research collaborations should emphasize a root cause analysis
- Institutional research committees and boards should have adequate numbers of community and patient representatives so their voices are heard and their presence is not tokenizing
- Embrace cultural humility

**Specific Actions UCSF Can Implement to Build Community Capacity as well as Support and Sustain Community Engagement for Health Equity and Anti-Racism in Research**

- UCSF should enter into equitable partnerships to meet community-identified needs and leverage the resources of UCSF in service to meeting those needs. Advocate for community members’ needs to build trust and relationships in the communities we work in (i.e., policy advocacy). UCSF should work with community members to promote and support what they need and want before we ask communities to help UCSF. It takes a long time to do this. Support long-term relationships to make this possible.*+
- Create/support infrastructure for capacity and skill building for community partners (including funding)*+
  - Create a Community Faculty designation for community research partner leaders
  - Establish and support a “matchmaking” platform where community members can connect with research groups on research topics of interest*+
  - Create/maintain list of defined communities
  - Reach out to identify leaders with the purpose of helping to build their communities’ capacity
  - Ensure that community research partners have access to library resources
  - Provide/include childcare provisions for community meetings regarding research
    - Example: Convene community town halls to bring people in to start conversation on what community groups need or want in order to participate in research
  - Researchers work with community partners before the research begins in activities to understand how communities understand health and wellness, e.g., do not just show up only for research
  - Build and support a two-way communications pipeline between communities and the university to ensure active, established and known avenues of communication to elicit community input on research priorities. This pipeline can support cross-advertising of events and resources as well*+
  - Financial support for community research partners should be relational, not transactional, committed to ongoing structural capacity building and based on trust
- Develop community research infrastructure
  - Create and support “Community Research Hub” located in community
  - Develop a fiscal sponsorship mechanism for community organizations
  - Provide training in translational science with the goal of incorporating community roles/leadership in the research*+
  - Provide training on how to write grants*+
  - Find research collaborators for community organizations*+, including affiliates of other academic institutions, not just UCSF.

- Patient and community engagement should be a part of UCSF’s Institutional Review Board (IRB) process*+
  - Example: Committees should have patients and community members serving with fair compensation.
- Require a patient and community engagement plan in the IRB application process.
- Create and support a community Institutional Review Board

**Specific Actions UCSF can Implement with its Researchers to Address Health Equity and Advance Anti-Racism in Research**

- **Challenge the concept of research “incentives” and address fair compensation for research participation and advising**
  - Encourage researchers to have community leadership in research projects, including as co-principal investigators
  - Facilitate language access, research teams with capacity to communicate in languages other than English. Ensure medical translators and interpreters
  - Require a clear community dissemination plan to ensure implementation
    - Ensure dissemination of research results back to the community that is being studied
    - Work with ethnic media to support dissemination and education efforts
    - Make research findings and results more accessible so communities and patients know what works. Need for research that leads to action and results
    - Ensure accessibility of research findings. Patients and community want to know they have been listened to and know what is happening in research
    - Provide access to public information about research, not just in research publications
    - Ensure there is time for dissemination and sustainability
    - Set up regular research townhall forums to disseminate research findings and discuss priorities with community and patient stakeholders

- **Assist/enable researchers to build community relationships to create safe, honest and equitable partnership**
  - Support infrastructure to maintain patients and community advisory boards to support and involve community at all stages of the research process from conception to dissemination. Avoid fragmentation and silos
    - Example: Provide researchers with free consultation and advisory board access to make community engagement easier for researchers (e.g., patient and community advisory boards)
  - Require early community engagement in research
  - Researchers should indicate on grant and IRB applications if/when they included formal community input from established community groups, preferably already in partnership with UCSF, in:
    - Determining what research is needed - ask community organizations what topics they would like additional research on
    - Participating at conceptualization phase of proposal development
    - Design of research question and/or implementation
    - Formalize relationship with community groups in the research process

- **Train researchers to do better in**:  
  - Understanding prior research in communities so replication/duplication does not happen
    - On the particular topic
    - On other health topics, as solutions may be cross-cutting and collaborative solutions more likely to succeed
- General principles, best practices, available resources for patient and community engagement in research to avoid having the same community input being given over and over again to individual researchers⁺
- *Budget for real costs, like translation*

- **Provide guides to research for patients/community members**⁺
- **Increase diversity among clinical research coordinators, research assistants/associates, on advisory boards and patient and family advisory councils**, and include them as leaders in the research
- **Mandatory community representation with adequate compensation along with infrastructure support required**
- **Support/provide transparency around failures (e.g., not getting grants funded, not achieving expected outcomes in projects)**

### UCSF Can Structure Its Funding and Other Incentives and Rewards to Address Health Equity and Advance Anti-Racism in Research

- **The system of measuring and rewarding success in academia is grants, publications, honorific appointments. This system does not promote equity goals and needs to change to reward community engagement/success**⁺
  - Success metrics determined by white males and subject to systemic racism
  - Recognize community engagement in promotion and other recognition
  - *Emphasize early community engagement in research*
  - *Tenure and promotion consideration should include public health impact of research*
  - *Reward relationships*

- **Provide pilot funding for researchers to work with community partners early in research process to ensure that research directly addresses community needs and that information generated can be translated into real social impact**⁺

- **Require community engagement for certain internal grant awards**

- **Require the use of plain language summaries for researchers in intramural applications and community interactions. The quality of this element should count toward the scoring of proposals.**

### Additional Actions UCSF Can Take to Promote Anti-Racism in Research

- **Increase the number and proportion of Black American researchers and other researchers of color at UCSF, with strategies for retention and advancement**
  - Address over-taxing the few research faculty and leaders from under-represented groups
  - Enable professional recognition for DEI work through incentives that compensate time

- *Educate people who approve budgets of the value of community engagement*

- *Support participatory budgeting - diversify groups that hold power*

- Collectively participate in policy advocacy and policy change with the historically oppressed communities and patients whose voices are not heard
  - One example is to advocate to funders including the NIH to emphasize patient and community engagement and fair compensation for research participation; identify internal and external policy changes to create opportunities for entry, retention, and
advancement of racial/ethnic minorities in research staff (especially managerial level where diversity is particularly poor)

- Strengthen partnerships with local colleges (SF State and CCSF) to diversify the research community and empower the next generation of local health and health science leaders