

BEFORE THE UNITED STATES OFFICE OF MANAGEMENT AND BUDGET

Request for Information: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government, 86 Fed. Reg. 24,029 (May 5, 2021)

Name of Respondent: LGBTQ Community Health Researchers

Areas of Response:

1. Equity Assessment and Strategy
3. Procurement and Contracting
4. Financial Assistance
5. Stakeholder and Community Engagement

Description of Organization:

The LGBTQ Community Health Researchers are research entities and health care centers that focus primarily on health inequities in populations of people living with or at risk of acquiring HIV; lesbian, gay, bisexual, transgender, and queer people (LGBTQ); and marginalized racial and ethnic minorities. Through research, education, advocacy and care we work to identify health disparities experienced by our priority populations. Our job is not only to identify the sources of health disparities among communities we serve, but we also work to address the impact of health disparities at the individual level during clinical care and on community and structural levels in our policy and research efforts.

The following organizations are submitting these comments:

Callen-Lorde Community Health Center, New York City, NY
Chase Brexton Health Care, Baltimore, MD
CrescentCare, New Orleans, LA
Howard Brown Health, Chicago, IL
Legacy Community Health, Houston, TX
Los Angeles LGBT Center, Los Angeles, CA
The PRIDE Study, Stanford University School of Medicine
Whitman-Walker Institute, Washington, DC

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COMMENTS OF LGBTQ COMMUNITY HEALTH RESEARCHERS

OUR EXPERTISE AND PERSPECTIVE

The authors of these comments are research entities and health care centers that focus primarily on health inequities in populations living with or at risk of acquiring HIV (PLWH); lesbian, gay, bisexual, transgender, and queer people (LGBTQ); and marginalized racial and ethnic minorities. Our mission is not only to identify the sources of health disparities among communities we serve, but we also work to address the impact of health disparities, at the individual level during clinical care, and at the community and structural levels in our policy and research efforts.

Our research programs arise from the period of the AIDS crisis and HIV epidemic and from serving people living or at risk for HIV and sexual and gender minorities. Our centers emerged from marginalized communities working to address unmet care needs for people living with HIV and LGBTQ communities, and our research activities are aimed at improving the care we provide to them. Consequently, the community-based perspective is embedded in our history and delivery of health care services.

Collectively, we have over 100 years of experience researching best practices for caring for LGBTQ people and PLWH. We conduct federally funded research projects, as both prime and sub-grantees. We have extensive experience in health care, with over 200,000 patients at our health care centers spread across the United States in California, Illinois, New Orleans, New York, Maryland, Texas, and Washington, DC. We represent the nation's foremost experts in HIV prevention and treatment and gender-affirming and patient-centered care. Our providers, researchers, community health workers and advocates are at the forefront of addressing health disparities indicative of persistent social inequities stemming from discrimination and exclusion.

Descriptions of the LGBTQ Community Health Researchers are contained in **Appendix A**.

The purpose of these comments is to highlight problems in the current system of how communities are engaged in health research into the issues that affect them, and to suggest ways to mitigate those problems and make health research more effective at addressing health disparities.

GAPS IN RESEARCH AMONG UNDERSERVED POPULATIONS CONTRIBUTE TO INEQUITIES

We [advocate](#) for widespread inclusion of LGBTQI people in health data collection and national surveys in ongoing efforts to identify health disparities. In particular, more research is needed to understand the health needs of intersex people. Funding community-based research can help identify the reasons why, when compared to the general population, LGBTQ people and people with intersex traits experience [worse health](#) outcomes. Moreover, community-led research is necessary to build interventions that address and ameliorate LGBTQ health disparities. We advocate for community-led research that is inclusive of the many intersecting identities that LGBTQ people hold.

As community health centers with special missions to underserved populations, much of our work is done within a context of a research participants' multiple intersecting identities and must be respectful of and responsive to all their needs. For an example at the intersection of LGBTQ identity and race, research shows that Black LGBTQ people experience markedly different health outcomes than their non-LGBTQ counterparts. The processes that address disparities in [economic, mental, and physical health](#) for Black LGBTQ people must be led by members of those communities. Not having community-led research perpetuates the historical silencing of marginalized people and contributes to continued health inequities in communities and worse health outcomes for individuals.

We can point to discrimination against LGBTQ people and [minority stress](#) as the source of disparities in mental health outcomes, including [suicidality](#), [substance use](#), and [anxiety and depression](#). However, research on interventions to improve mental and behavioral health of LGBTQ communities must be culturally appropriate and designed to produce results that will lead to clinically effective interventions, and so should be guided by the leadership of LGBTQ people. Additional research with community partners can promote acceptable interventions to address health disparities in underserved populations, by providing guidance to clinicians in provider-patient interactions and by identifying interventions that address underlying discrimination and bias.

Research teams that are diverse and grounded in community are better able to identify and respond to the unique needs of these populations. For example, in some segments of the LGBTQ communities, in particular [transgender men, nonbinary people](#), bisexual people, people who identify as asexual, and people with intersex traits, there is very little research on their health needs and experiences in health care settings. More support of and investment in community-based participant research models for all underserved communities can address these gaps in knowledge and support ethical and effective health interventions.

COMMUNITY-BASED RESEARCH MODELS ADDRESS HEALTH INEQUITIES

Our experiences serving LGBTQ and other underserved communities guide our recommendation of a community-centered approach to understanding and solving health inequities. As community-based medical, research, education, and policy experts advocating for health and wellness, we recognize that it is paramount to involve communities experiencing health inequities in identifying and answering questions about the sources of inequity and solutions to bring about equity. Communities are the experts at understanding their own lived experiences and treating them as such is foundational to building equity.

The Agency for Healthcare Research and Quality (AHRQ) has developed an extensive theoretical framework for engaging in community-based participatory research.¹ These processes, when implemented effectively, represent a more ethical distribution of power in research, reflect the needs of community members, improve the durability of partnerships between research institutions and communities, and are action-oriented and transparent in seeking change in the communities where implemented, thus addressing social inequities at their source. However, as discussed in the next section of these comments, current federal practices for funding and guiding health research affecting LGBTQ populations falls short of the promise of these guidelines for community-centered research.

Research that centers on community needs has unrealized potential for truly meaningful engagement with marginalized communities, expanding this engagement to authentic partnerships, and understanding social needs. To address deeply embedded inequities, community-based health research needs to bridge the divide between academic inquiry and clinical practice to transform government and health services.

CURRENT RESEARCH MODELS UNDERINVEST IN COMMUNITY ENGAGEMENT

Currently, research proposals are required to include community engagement plans, and are sometimes highlighted to show connection to community, but this priority often gets crowded out by other grant responsibilities, and so becomes a pro-forma activity. Community engagement, far from being a single, often siloed activity in health services research, should be central to the development of research questions.

Researchers at community health centers often participate in community engagement process with prime grantees. These community engagement grants are often accompanied by unrealistic expectations and promise outcomes that do not align with the resources that are available to fulfill them.

¹ AHRQ Activities Using Community-Based Participatory Research to Address Health Care Disparities. Content last reviewed April 2020. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/research/findings/factsheets/minority/cbprbrief/index.html>.

Wilson E. (2018) Community-Based Participatory Action Research. In: Liamputtong P. (eds) Handbook of Research Methods in Health Social Sciences. Springer, Singapore. https://doi.org/10.1007/978-981-10-2779-6_87-1.

Jenkins, R.A. (2007). Editorial: Challenges in Engaging Community Participation in HIV Prevention Research. *Progress in Community Health Partnerships: Research, Education, and Action* 1(2), 117-119. [doi:10.1353/cpr.2007.0009](https://doi.org/10.1353/cpr.2007.0009).

Aguado Loi (C.X.) et. al. (2017) Application of mixed-methods design in community-engaged research: Lessons learned from an evidence-based intervention for Latinos with chronic illness and minor depression, *Evaluation and Program Planning*, Volume 63, Pages 29-38, ISSN 0149-7189, <https://doi.org/10.1016/j.evalprogplan.2016.12.010>.

From our experience, academic institutions with substantial administrative resources often are awarded grants as lead agencies, while community partners are engaged as subcontractors to do participant recruitment, often packaged as community engagement, and study implementation. Subcontractors receive far less of the grant budget allocation and fewer of any other investments and resources compared to prime grantees.

For example, we have experienced instances where an academic institution will approach a community health center to collaborate on a grant and share a theory-based model for the work. In response, the community partner then teaches the academic institution the practice-based model for the work. In turn, the academic institutions incorporate the community partners' work into their research, oftentimes using the model for their research and garnering recognition as a best practice or other accolades when they publish. Community partners' practice-based insights and innovations are critical to the research development, shaping methodology, and demonstrating important conclusions and best practices but often we are not compensated or recognized for co-design. This example highlights how the community health center or partner can be key to the research project and outcomes but not recognized – financially or in the research publication process – as an equal partner.

Unfortunately, this dynamic does not invest in the organizations that are oftentimes producing the innovation and carrying out the work. The current structure feeds inequity and undervalues the community experience that generates the innovations and knowledge we need to improve the health and wellbeing of our patient populations. The aforementioned system perpetuates a cycle wherein community relationships and community organizations are under-resourced and consequently struggle to invest in the capacities needed to become primary grant recipients.

There is a pressing need to develop new funding structures that can support the engagement of communities in all phases of research. The NIH and CDC recognize the need to focus on it; however currently, there is limited support and infrastructure to invest in the depth and scope of community engagement necessary to address inequities in the research process and in the implementation of research findings. Community-based organizations that seek to bridge the gaps in research often perform the task of convening community or specific populations without funding. This work is done to ensure voices are included and to position themselves to partner on research opportunities. However, formally recognizing the need for support and infrastructure and providing the necessary funding is needed to reach the goal of more structured community engagement.

Current research mechanisms necessitate the need for a well-developed study plan prior to submitting a grant for funding, yet there are not adequate funding mechanisms to engage communities in a meaningful way in the planning portion of the project. To improve outcomes, community engagement processes and resources should be provided prior to what would normally be the funding period for a grant. What is needed in an extension of the timeline for research projects and expansion of the scope of community engagement goals.

Funding mechanisms can function to support more authentic community engagement in research throughout the process, including initial identification of health and wellness-related questions of most importance to the community in question. Non-academic research institutions, including community health centers and other community-based non-profit organizations, are substantially less likely to seek and obtain NIH funding for research due to misalignment between research funding requirements and internal infrastructure and resources to meet these requirements. In particular to the NIH, which allocates the [vast majority](#) of federal spending on health research, there is misalignment between the goal of community-based research and the NIH's funding structures.

RECOMMENDATIONS FOR INCLUDING COMMUNITY-BASED ORGANIZATIONS IN NIH RESEARCH OPPORTUNITIES

The following are opportunities for greater alignment in NIH funding opportunities and community health research structures:

- (1) There is inadequate funding for research training and mentorship to occur within community-based organizations rather than traditional academic environments. The NIH should create funding streams for scientists and scientist-practitioners to train in community-based settings and build lasting infrastructure within community-based settings to conduct their work.
- (2) There is a lack of funding to support the development of community-driven research agendas that can lead to new and innovative research grants. The NIH should create new funding mechanisms with extended community engagement timelines to rigorously develop research agendas in equal partnership with communities to develop new research studies. Building respectful and trusting relationships with communities to enable meaningful engagement takes time. Communities need time for engagement and then time for the additional work needed to identify and articulate the communities research needs and priorities.
- (3) There is a lack of funding to support implementation of evidence-based practices after completion of a research trials. There is rarely funding available for communities to continue the work once a typical grant period is over. For research to address inequity, their needs to be meaningful investment in the post-research adoption and dissemination phase, which would occur after what would normally be the funding period. The NIH should partner with other federal organizations to create mechanisms to incentivize researchers to continue partnering with organizations to sustain the work done within a completed NIH-funded trial.
- (4) Currently, in research applications there is a narrow focus on individual investigators and their careers rather than on collaborative programs of research. We recommend that NIH create funding mechanisms that prioritize teams and organizations over individual scientists and broad programs of research over narrowly defined individual studies. We believe this broadens the opportunity invest in a diversity of sources of advancement and innovation in health research.

(6) Similarly, NIH grants focus on program funding to support long-standing, well-funded centers rather than develop new, community-embedded centers of excellence and other programs. We recommend that NIH create new funding opportunities to support non-academic research centers or collaborative networks of community-based organizations.

(7) There is a bias within the current review process that academic faculty status is necessary for Principal Investigators to succeed, which undermines the ability for community-embedded researchers to compete, and potentially drives them to leave community-based organizations for more academic research environments – perversely resulting in more distance between them and the communities that they want to help. We recommend that NIH create specific mechanisms or incentives for researchers, particularly from underrepresented backgrounds, to conduct research within community-based organizations.

(8) There are inadequate resources for community-based organizations to establish appropriate Facilities & Administrative rates to support the development of research programs. NIH can modify policies to raise the non-negotiated Facilities & Administrative rate for community-based organizations who are developing research programs and provide infrastructure funding to support developing an administrative environment to sustain a research program.

These changes support community-based organizations to do thorough, high quality health research that is authentically responsive to the communities we serve.

CONCLUSION

These specific suggestions are part of a larger project to shift how research is funded. As community-based research institutions, we urge a greater role for our researchers as the support entities for achieving equity goals. It cannot be only academic institutions that drive and lead the research. Community members with lived experience should drive the research questions. Communities can work in partnership with researchers, but these partnerships take time and investment.

Thank you for this opportunity to provide information on building health equity for underserved communities. Our researchers are available to engage in more in-depth discussion of these issues and to assist in developing needed reforms.

Respectfully submitted,

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APPENDIX A

ABOUT THE LGBTQ COMMUNITY HEALTH RESEARCHERS

About Callen-Lorde Community Health Center: Callen-Lorde provides sensitive, quality health care and related services for New York’s LGBTQ communities — in all their diversity — regardless of ability to pay. Callen-Lorde is the global leader in LGBTQ healthcare. Since the days of Stonewall, we have been transforming lives among LGBTQ communities through excellent comprehensive care, provided free of judgment and regardless of ability to pay. To further this mission, Callen-Lorde promotes health education and wellness for LGBTQ people, and advocates for LGBTQ health issues. Callen-Lorde’s grassroots heritage dates back 50 years to the St. Marks Clinic and the Gay Men’s Health Project – two volunteer-based clinics that provided safe and confidential sexual health and primary care regardless of ability to pay. These clinics merged in 1983 to form Community Health Project, a mostly volunteer-staffed, episodic care program housing the nation’s first community-based HIV clinic. In addition, we are continuously pioneering research, advocacy, and education to drive positive change around the world, because we believe healthcare is a human right. Callen-Lorde serves as a center of excellence – helping to train the future leaders in LGBTQ health while blazing new trails through research and other strategic partnerships.

About Chase Brexton Health Care: The Center for LGBTQ Health Equity is part of Chase Brexton Health Care, a Federally Qualified Health Center with expertise in LGBTQ health care and HIV care. Founded in Baltimore’s Mt. Vernon neighborhood in 1978, Chase Brexton began as a volunteer-run gay men’s health clinic. Our work took on a new and difficult challenge in the early 1980s when we became one of the first clinics on the front lines of the fight against HIV and AIDS. After seeing the needs of the family and loved ones of those we served, we expanded our services, adding Behavioral Health and Social Work services in 1991 and finally expanding to full Primary Care services in 1995. Chase Brexton became a Federally Qualified Health Center in 1999. Two years later, Chase Brexton earned accreditation in both Ambulatory and Behavioral Health from The Joint Commission. Since our founding in Baltimore’s gay community, we have remained committed to providing individualized care that respects and empowers patients of all ages, races, gender identities, religions, sexual orientations, ethnicities, and socioeconomic statuses. Providing care that honors, affirms, and supports each patient is at the core of everything we do. Whether new to the community or new to the country, with or without insurance, gay or straight, all are welcome and will receive compassionate, quality care at Chase Brexton.

About CrescentCare: CrescentCare (previously NO/AIDS Task Force) is a non-profit, 501(c)3 community organization founded in 1983 that has historically provided HIV/AIDS services throughout southeast Louisiana. In 2013, CrescentCare expanded its mission and became a Federally Qualified Health Center, providing medical care and supportive services to a broader community beyond people living with HIV. CrescentCare now serves approximately 14,000 individuals with primary care, behavioral health, and dental services at two primary care clinics in the New Orleans area. Over the last five years, CrescentCare has engaged in several NIH,

CDC and non-governmental sponsored research trials that support the primary care and prevention focus of the organization.

About Howard Brown Health: Howard Brown Health (Howard Brown) is the largest LGBTQ health center in the Midwest United States, serving over 38,000 patients across 12 clinic locations in Chicago, Illinois. As a federally qualified health center, Howard Brown provides comprehensive, high quality and affordable care—including primary care, behavioral health, mental health services, HIV/STI prevention, and sexual and reproductive healthcare—to all our patients, regardless of ability to pay. Howard Brown’s mission is to eliminate LGBTQ health disparities, and one way that we advance that mission is through our research programs. Howard Brown’s research activities began in the late 1970s when the organization first identified high rates of hepatitis B (HBV) among its patients. Howard Brown initiated a new research program that eventually helped lead to the development of the Hepatitis B Virus vaccine. Since then, Howard Brown has been involved in nationally funded research initiatives aimed at addressing critical disparities in LGBTQ health, focused on HIV/AIDS treatment and prevention, infectious disease, smoking cessation and preventive care, gender affirming care, and implementation and evaluation studies. Howard Brown’s Center for Education, Research and Advocacy (ERA) conducts rigorous community-based clinical and behavioral research, supports the next generation of LGBTQ healthcare professionals, and advances policies that affirm the lives of LGBTQ people. ERA develops and disseminates community-driven, evidence-based, high quality best practices in LGBTQ health.

About Legacy Community Health: Throughout the last 45 years, Legacy Community Health Services (Legacy) has evolved from a small neighborhood sexually transmitted disease clinic to a full-service Federally Qualified Health Center (FQHC) focused on providing primary care, dental care, vision services, behavioral health services, family planning, health promotion and community outreach, wellness and nutrition, and comprehensive HIV/AIDS care. Legacy first opened its doors to the LGBTQ+ community in 1978 as the Montrose Clinic, whose focus was helping HIV-positive Houstonians. In the three decades that followed, we have expanded our scope of services to become a nationally recognized leader in HIV/AIDS primary care, prevention, and treatment. And as we grew larger, our dedication to serving LGBTQ+ patients with dignity, respect, and compassion grew stronger. Legacy’s medical and behavioral specialists, staff, and consultants recognize that LGBTQ+ patients often have unique needs that require equally unique responses. Given our roots, we have the range of experience and expertise to bring health, hope, and peace of mind to our LGBTQ+ patients, regardless of what issues they may be facing. Legacy actively engages in research initiatives that address LGBTQ+ health issues, including initiatives through the Patient-Centered Outcomes Research Institute (PCORI). Legacy is currently collaborating with PCORI on Comparative Effectiveness Research to Improve the Health of Sexual and Gender Minority Patients Through Cultural Competence and Skill Training of Community Health Center Providers and Non-Clinical Staff.

About Los Angeles LGBT Center: Since 1969, the Los Angeles LGBT Center (Center) has cared for, championed, and celebrated LGBT individuals and families in Los Angeles and beyond. Today the Center's over 800 employees provide services for more LGBT people than

any other organization in the world. The Center is one of the few Federally Qualified Health Centers in the nation with providers who specialize in primary care and HIV/AIDS medical care for LGBT people. In addition to our health services, we offer residential services for youth and seniors, drop-in services for homeless persons, immigration assistance, meal services, and so much more. Across all our programs, we see over 50,000 clients per month; or, over half a million visits each year. In this moment, the need for our services has never been greater.

About The PRIDE Study: [The Population Research in Identity and Disparities for Equality \(PRIDE\) Study](#) is a community-engaged, online, national, longitudinal, dynamic, prospective, cohort study of self-identified LGBTQ+ people. Founded in 2017 to counteract the lack of data describing the health-related needs of LGBTQ people, The PRIDE Study engages, recruits, and enrolls adults living in the United States who identify as LGBTQ+ to collect and report demographic, physical, mental, and social health data and outcomes. The PRIDE Study is based in Palo Alto, California and is a study of Stanford University School of Medicine in partnership with the University of California, San Francisco.

About Whitman-Walker Institute: Whitman-Walker Institute is one of the country's premiere organizations focused on advancing the health and wellbeing of people facing barriers to quality care, particularly LGBTQ people and people living with HIV, through the strategic integration of clinical expertise, research acumen, quality education and policy change. The Institute endeavors to remain grounded in community by seeking feedback and promoting ideas that reflect the lived experiences and identified needs of those we serve. The Institute conducts cutting edge research and engages in evidence-based education and policy advocacy to end the HIV epidemic, eliminate health disparities, and promote wellness and resiliency. The Institute has conducted clinical research trials since 1987, studying nearly every HIV and Hepatitis C treatment available on the market today. We partner with other LGBTQ-serving health care and research centers across the U.S. in the *We Count Collaborative* to study the impact of COVID-19 on our patients. 49 percent of the Institute's research participants are people of color. Many of the Institute's research participants identify as LGBTQ (at 70 percent), and 7 percent are transgender or gender expansive. Among the women in our research program, 90.7 percent are women of color, 27.8 percent are LGBQ+, and 32.5 percent are transgender and gender expansive. Our current research portfolio includes studying the long-term effects of HIV medications, technology-mediated health interventions, and health services translational research for communities of color and LGBTQ communities. Through such work, we empower all persons to live healthy, love openly and achieve equality and inclusion.