

BEFORE THE UNITED STATES NATIONAL INSTITUTES OF HEALTH

Request for Information on Research Opportunities and Operational Activities Related to the NIH Strategic Plan to Advance Research on the Health and Well-Being of Sexual & Gender Minorities Fiscal Years 2021-2025

86 Fed. Reg. 54224 (September 30, 2021)

We, LGBTQIA+ community health researchers, advocates, and practitioners, welcome the opportunity to provide comment on the NIH Strategic Plan to Advance Research on the Health and Well-Being of the Sexual and Gender Minorities (SGM). As with many minoritized and stigmatized populations, the health and well-being of SGM communities are indicative of the wider health inequities and social disparities which the Biden-Harris administration has so rightly focused their energy on addressing.

Generally, we find that the NIH SGMRO's strategic plan identifies relevant research areas and opportunities to better understand and ameliorate many health disparities and disproportionate disease profiles present in sexual and gender minority communities. Based on our expertise, we would like to offer the following recommendations for research opportunities, expanding the research capacity of community-based organizations, and improving equity in federally funded research.

Contact:

Benjamin Brooks, Assistant Director of Policy, Whitman-Walker Institute
bbrooks@whitman-walker.org

A note on terminology:

In these comments, most often we use "LGBTQIA+" to describe the communities that we serve and of which we are a part. When fewer letters are used (e.g. LGB, LGBT), this describes the limits of the research being discussed in that section. When appropriate, sexual and gender minorities (SGM) is also used to denote the specific concerns of people with minoritized sexual and gender identities and to align with NIH terminology.

OUR EXPERTISE AND PERSPECTIVE

The authors of these comments are advocates, 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, queer, intersex, and asexual people (LGBTQIA+); marginalized and minoritized racial and ethnic groups; and SGM communities. Through research, education, advocacy and care we work to identify health disparities experienced by our priority populations. Further, our task is not only to identify the sources of health disparities among communities we serve, but we also 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.

Collectively, we have years of experience researching best practices for caring for LGBTQIA+ people and PLWH. We conduct federally funded research projects, as both prime and sub-

grantees. We have extensive experience in health care, with many thousands of patients at our health care centers spread across the United States. 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.

EXISTING OPPORTUNITIES TO ADVANCE RESEARCH ON LGBTQIA+ HEALTH PRIORITIES

We provide these comments on the potential areas for research on SGM health disparities to ameliorate the health inequities that many LGBTQIA+ communities experience.¹

Impact of policies and services on SGM health

Policies and services vary significantly across municipalities and states. What policies and targeted services correlate with greater resiliency, health and well-being? Do health care entities need technical support to implement anti-discrimination policies? More and more health organizations have sexual orientation and gender identity (SOGI) nondiscrimination policies, while some states and the federal government have adopted policies that could increase anti-LGBTQIA+ discrimination in health care and restrict access to care. Anti-LGBTQIA+ discrimination is linked to negative physical and mental health outcomes, and discrimination in health care settings creates barriers to seeking necessary and preventative medical treatment.² Many states and cities have adopted targeted services for LGBTQIA+ elders, youth, and other populations. Research on the impact of pro- and anti-LGBTQIA+ policies and of targeted services on health and well-being is needed.

SGM older adults

Research to evaluate the effectiveness of group-level and community-level interventions to promote community and reduce social isolation among LGBTQIA+ older adults is needed, especially with programs and interventions that receive funding through the Older Americans Act. Social isolation is of particular concern for LGBTQIA+ elders because they are less likely to have children and more likely to live alone compared to their heterosexual peers.³ Furthermore, LGBTQIA+ elders may be afraid to access mainstream elder services due to fear of discrimination, and this can exacerbate social isolation. Interventions to promote community and reduce social isolation include congregate meal programs, LGBTQIA+ elder bereavement groups, LGBTQIA+-friendly congregate housing, and other interventions.

More research is necessary to study the experiences of LGBTQIA+ elders and older adults living with HIV in senior service settings, where age peers are more likely than other age cohorts to hold homophobic views and to be misinformed about how HIV is transmitted. This research

¹ Portions of this section are excerpted from the January 24, 2020 comments submitted by The Fenway Institute in response to the NIH's SGMRO Request for Information on the Development of the Fiscal year 2021-2025 Trans-NIH Strategic Plan for Sexual and Gender Minority Health Research.

² Lambda Legal. (2010.) *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

³ Fredriksen-Goldsen KI, Kim HJ, Emlert CA, Muraco A, Erosheva EA, Hoy-Ellis CP, ...Petry, H. (2011). *The aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Seattle: University of Washington, Institute for Multigenerational Health.

could inform interventions, changes to services, and best practices to ensure that they can access elder services.

Research on transgender and intersex elders is especially needed. Transgender elders can experience family rejection from children and rejection from LGB community members. They often experience culturally incompetent care from elder service and care providers.⁴ Even less is known about the experiences of older adults with intersex traits, who may face similar barriers.⁵

Lesbian and bisexual women's health

There is a dearth of research on the health issues affecting lesbian and bisexual women. We need more disparities research and intervention research in chronic disease among sexual minority women, including cardiovascular health, stroke, functional impairments, BMI, asthma, cancer— including colorectal and lung cancer. Sexual minority women often report high prevalence of stigma and discrimination resulting in higher rates of depression and other behavioral health disparities, with bisexual women reporting higher rates than both their lesbian and heterosexual counterparts.⁶

More research is needed on the interactions between hormone replacement therapy (HRT) and reproductive health. There are opportunities for advancements in knowledge of hormone interactions with fertility, family planning options for transgender and intersex people, polycystic ovarian syndrome, endometriosis, and cervical cancer. These are particular areas of research for advancement of the equity for people who live at the intersection of Black and LGBTQIA+ identities. Additional research is needed on the experiences of trans women and men, non-binary people, and intersex people with breast cancer, conception and pregnancy, lactation, whether and how these may be affected by hormone therapy.⁷

Incarcerated LGBTQIA+ adults and youth in juvenile justice systems

LGBT people are overrepresented in adult prisons and jails and youth systems. One in 18 (5.6%) of U.S. adults identifies as LGBT,⁸ while 9.3% of men in prison and 42.1% of women in prison identify as sexual minorities.⁹ Prisons and jails are a source of trauma and ill health for

⁴ Cahill S. (2017). Research and policy change to improve health care and elder services for LGBT older adults. *LGBT Health*. 4(6): 381-383.

⁵ Talley, H. L., & Casper, M. J. (2011). Intersex and aging: A (cautionary) research agenda. In Gay, Lesbian, Bisexual, and Transgender Aging: Challenges in Research, Practice, and Policy (Vol. 9781421404059, pp. 270-289). Johns Hopkins University Press.

⁶ Bostwick W. (2012, May 18). Assessing Bisexual Stigma and Mental Health Status: A Brief Report. *Journal of Bisexuality*. 12(2): 214-222.

⁷ Ross, N ., Westrup, Y ., Hwang, B .J ., Sierra, L ., Nordstrom, A ., Krysiak, R .C ., Jordan, S .P ., & The Four Corners: TNB Health Research Advisory Network. (2021). Four Corners: Health Research Priorities Among TNB Communities.

⁸ Jones JM. LGBT identification rises to 5.6% in latest US estimate. Gallup News. <https://news.gallup.com/poll/329708/lgbt-identification-rises-latest-estimate.aspx>. Published February 24, 2021. Accessed December 1, 2021

⁹ Meyer I, Flores A, Stemple L et al. (2017). "Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011–2012." *Am J Public Health*. 107(2):234–240. The data that Meyer et al.

incarcerated people as they are separated from social supports in restrictive environments. Rates of many mental illnesses are higher for people incarcerated in prisons and jails than for the general population.¹⁰ More research is needed to evaluate the outcomes of policies that promote incarceration. More funding is needed to evaluate programs that promote alternatives to incarceration to identify which policies and practices prevent recidivism, encourage successful re-entry in communities, and build resilience among returning citizens.

LGBT people who are incarcerated experience much higher rates of sexual victimization and violence victimization than heterosexual, cisgender inmates.¹¹ The Prison Rape Elimination Act is being implemented to reduce this disparity and end prison rape, yet we have anecdotal evidence from formerly incarcerated LGBTQIA+ people that PREA is being misused to single out and hyperpolice their behavior, often resulting in their being held in solitary confinement for no legitimate reason. Culturally competent collection of SOGI and intersex data within corrections and juvenile justice systems and research on the experiences of LGBTQIA+ people in corrections and juvenile justice settings is needed.

Long-term survivors with HIV and older adults living with HIV

NIH should fund large-scale, national, longitudinal studies that investigate how antiretroviral medications and HIV disease interact with aging bodies, and how they interact with treatments for comorbidities such as high cholesterol medication. Additional areas of research that should be pursued include: the extent to which the normal aging processes are accelerated as a result from viral infection and immune activation from long-term HIV treatment; the incidence and determinants of cognitive decline in aging HIV-positive individuals; and social interventions to improve behavioral health and reduce isolation among long-term survivors with HIV.

SGM youth

Research is needed on how best to promote parent-child conversations about sexual health and healthy dating, HIV/STI/pregnancy prevention, and identity formation and support for SGM youth. Lack of knowledge about safer sex strategies—for example, use of lubricants with condoms—and concerns about being outed are common barriers to accessing sexual health services for SGM youth. LGBTQIA+ youth also experience barriers to sexual health care common to youth in that age group, such as cost and embarrassment, and barriers to HIV screening, such as fear of getting an HIV diagnosis and the perceived exorbitant cost of treating HIV. HIV prevention and comprehensive education interventions involving both youth and parents that address these concerns are needed.

Many SGM youth, especially gay and bisexual males and transgender youth, also experience self-esteem, body image, and disordered eating issues. Low self-esteem can make it more difficult to navigate sexual situations and advocate for safer sex strategies with potential partners.

analyze is from: Beck AJ, Berzofsky M and Krebs C (2013). Sexual Victimization in Prisons and Jails Reported by Inmates, 2011–12 National Inmate Survey, 2011–2012. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics <https://www.bjs.gov/content/pub/pdf/svpjri1112.pdf>

¹⁰ Prins SJ. Prevalence of mental illnesses in US State prisons: a systematic review. *Psychiatr Serv.* 2014;65(7):862-872. doi:10.1176/appi.ps.201300166

¹¹ Beck AJ and Johnson C (2012). Sexual victimization reported by former state prisoners, 2008. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. <http://www.bjs.gov/content/pub/pdf/svrfsp08.pdf>

In the case of transgender and intersex youth, dysphoria and stigma surrounding their bodies can also play a major role in relationships and sexual encounters. Research to develop interventions to improve self-esteem and self-advocacy, especially in terms of dating, relationships, and sexual communication, is needed.

Most youth cannot access school-based sexual health education that is inclusive of same-sex behavior and SGM experiences. Adults serving youth, such as school nurses and adolescent health providers, can play a key role in health education. Youth also want age peers to deliver sexual health messages. Research is needed to inform and evaluate best practices for promoting sexual health education, especially in rural and socially conservative districts. NIH should also support research to develop innovative ways to reach youth using social media and technology with LGBTQIA+-inclusive sexual health information.¹²

Intervention research to promote resiliency through Positive Youth Development, family acceptance and other approaches is also needed.

Research and education on the outcomes of gender affirming care for non-binary and gender expansive transgender people

There is a lack of research and education on outcomes for non-binary and gender expansive people to inform decision-making. Many of the existing studies related to hormone therapies have not been conducted with non-binary and expansive transgender people in mind. Many trans and gender expansive people could benefit from access to information and education related to the effects of hormone therapy, interactive effects, and administration methods.

Other needed research on transgender and gender diverse people

Transgender and gender diverse (TGD) people, especially Black, Indigenous, Latine, and other TGD people of color, experience widespread social stigma, violence and marginalization, including in health care. These social determinants of health significantly affect the health and well-being of TGD people. Research on how to optimize access to gender affirmative care, and how to address health care institutional transphobia is critically needed. Implementation science research on how to improve access to health care and critical social services for TGD populations is needed.

Asexual health research¹³

Research indicates that asexuality is not a sexual or mental disorder, but instead is a variation in human sexuality.¹⁴ Asexual individuals, also known as people on the ace spectrum, have unique physical and mental health needs. Because asexuality is often pathologized, asexuals may face

¹² Cahill SR, Wang T, Fontenot HB, Geffen S, Conron K, Mayer KH, Johns MM, Avripas SA, Michaels S, Dunville R (2021, September-October). Perspectives on sexual health, sexual health education, and HIV prevention from adolescent (13 to 18 years) males attracted to males. *J Pediatr Health Care*. 2021;35(5):500-508. doi:10.1016/j.pedhc.2021.04.008

¹³ Adapted from Asexual Health. Dalla Lana School of Public Health. University of Toronto. Re:searching for LGBTQ2S+ Community Health. <https://lgbtqhealth.ca/community/asexual.php>

¹⁴ Gupta, K. (2017). What Does Asexuality Teach Us About Sexual Disinterest? Recommendations for Health Professionals Based on a Qualitative Study With Asexually Identified People, *Journal of Sex & Marital Therapy*, 43:1, 1-14, DOI: 10.1080/0092623X.2015.1113593

misdiagnoses and improper treatment in primary care, and experience inappropriate treatment in therapy and mental healthcare. The limited research that exists on this population indicates that asexual individuals experience a higher prevalence of suicidality, anxiety, depression, and interpersonal problems than heterosexual individuals.¹⁵ More research is needed to understand and interrupt these dynamics and to develop educational interventions to improve culturally relevant and affirming care for asexual people.

Studies of interventions to enhance clinician ability to provide culturally competent care for SGM patients

LGBTQIA+ people face widespread discrimination in health care, such as being verbally or physically harassed or being denied treatment altogether.¹⁶ This discrimination acts as a barrier to seeking necessary routine, preventive care as well as emergency care. For example, the 2015 U.S. Transgender Survey of nearly 28,000 transgender people found that in the last year, 33% of respondents had experienced anti-transgender discrimination in health care, and 23% of respondents chose to forego necessary health care due to fear of discrimination.¹⁷ A 2018 survey by the Center for American Progress found that 14% of LGBT respondents who had previously experienced discrimination in health care avoided seeking necessary medical care, and 17% avoided seeking preventive care in the past year.¹⁸ As such, it is critical to evaluate interventions that are meant to enhance clinician ability to provide culturally competent care for SGM patients. More research is needed on how implementation of education and capacity building efforts for providers can expand access to gender affirming care. Effective interventions should be disseminated widely in order to create more welcoming and affirmative clinical spaces for SGM individuals across the country.

The SGMRO should advance the development and study of digital health interventions and equity that can enable culturally affirming care (e.g., telehealth). There is a need for research on the development of new/updated quality measures that are inclusive of LGBTQIA+ people (e.g., cervical cancer screening for those who have a cervix as opposed to only including women).

Intersex people

Like other SGM people, there are many opportunities to advance research on the health and needs of intersex people. NIH has done some important foundational work in developing and highlighting its intersex research portfolio, but the SGMRO should work to increase the size and diversity of this small portfolio.

Since NIH's portfolio depends in part on the proposals it receives, NIH should prioritize promoting this research through (1) ensuring new resources, training, workshops, notices, and grant mechanisms include meaningful consideration of intersex populations, as well as intersex

¹⁵ Yule, M.A., Brotto, L. A., Gorzalka, B. B. (2013). Mental health and interpersonal functioning in self-identified asexual men and women. *Psychology & Sexuality*, 4, 136-151. doi.org/10.1080/19419899.2013.774162

¹⁶ Lambda Legal. (2010.) *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

¹⁷ James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality.

¹⁸ Mirza S and Rooney C. (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress.

investigators, and (2) increasing published resources, communications, and training opportunities for ICOs and external stakeholders that are focused specifically on intersex populations. In particular, NIH should host convenings on focused squarely on key research opportunities for intersex populations, and consider a multi-phase scientific workshop to develop research priorities, similar to the recent workshop on violence and SGM communities.

There is a need for methodological research with the goal of producing validated demographic survey measures for intersex youth and adult populations.¹⁹ In addition to promoting primary data collection, NIH should promote and fund efforts to identify and understand the experiences of intersex populations using retrospective review of clinical and claims data—building on efforts pioneered by federal researchers with transgender populations.

While a scientific workshop would be invaluable in refining a prioritized research agenda, NIH should start by prioritizing research on the outcomes for patients who experienced early “normalizing” interventions, compared with those who experienced a “watchful waiting” approach—especially studies that follow youth longitudinally, compare intervention and non-intervention groups, or employ mixed-methods assessments. Outcomes of particular interest would include:

- Psychosocial and mental health outcomes,
- Surgical complications or revisions,
- Sexual and reproductive health and wellness, including (but not limited to) fertility, sexual function and sensation, pain, scarring, urinary function, and cancers; satisfaction and perceptions of interventions or non-interventions, including (but not limited to) satisfaction with outcomes for sexual and reproductive health and function, and
- Experiences and outcomes of disclosure, discussion, education, or concealment regarding intersex traits in childhood and adolescents.²⁰

In addition, NIH should promote and fund evaluation of psychosocial interventions and decision tools to support intersex children and youth and their families.²¹ We need descriptive research to understand current practices for medical management of intersex infants, youth, and children, including informed consent and decision-making practices.²² Research is also needed on health professionals’ and hospital administrators’ views of relevant clinical, ethical, and standards for

¹⁹ See, e.g., S. Tamar-Mattis et al, Identifying and Counting Individuals with Differences of Sex Development Conditions in Population Health Research, *LGBT Health* 2018 5:5, 320-324.

²⁰ See, e.g., Mandy Henningham & Tiffany Jones (2021) Intersex students, sex-based relational learning & isolation, *Sex Education*, 21:5, 600-613; Tove Lundberg, Katrina Roen, Carina Kraft & Peter Hegarty (2021) How young people talk about their variations in sex characteristics: making the topic of intersex talkable via sex education, *Sex Education*, 21:5, 552-567.

²¹ See, e.g., Limor Meoded Danon & Katinka Schweizer (2021) Psychosocial approaches and discursive gaps in intersex healthcare: findings from an Israeli–German action research study, *Culture, Health & Sexuality*, 23:4, 441-456.

²² See, e.g., Garland F, Thomson M, Travis M, Warburton J. Management of ‘disorders of sex development’/intersex variations in children: Results from a freedom of information exercise. *Medical Law International*. 2021;21(2):116-146; Michala L, Liao LM, Wood D, Conway GS, Creighton SM. Practice changes in childhood surgery for ambiguous genitalia? *J Pediatr Urol*. 2014 Oct;10(5):934-9; Liao LM, Green H, Creighton SM, Crouch NS, Conway GS. Service users' experiences of obtaining and giving information about disorders of sex development. *BJOG*. 2010 Jan;117(2):193-9.

medical management of intersex youth.²³ Longitudinal research is need on management and outcomes of hormone replacement therapy for intersex adolescents and adults throughout the life span.

Research on parents' perspectives, stressors, and adaptation to a child's intersex traits during childhood, adolescence, and adulthood could help identify potential risk and protective factors, including peer and family attitudes, affirming or rejecting behaviors, stigma and discrimination, and experiences of identity development and coming out. Research could also examine the content of K-12, undergraduate, and medical curriculum regarding variations in sex characteristics, and the impacts of curriculum.²⁴

SGM people with disabilities

We need more research on disabled LGBTQIA+ people, including SGM people with intellectual disabilities and those who are deaf or blind. Research has shown that there is higher prevalence of disability among SGM populations. For example, one study of 2003, 2005, 2007, and 2009 BRFSS data found a higher prevalence of disability among LGB adults compared with their heterosexual counterparts that remained significant after controlling for various covariates of disability.²⁵

Vaping

Vaping is a potentially dangerous newer phenomenon that requires more research in general. Research has shown that the prevalence of e-cigarette use is high among LGBT people, especially among younger LGBT people.²⁶ Research on use of tobacco and non-tobacco products is needed. Research is needed to develop prevention and cessation interventions specifically targeted towards LGBT people, drawing from and building upon the mixed experience with LGBT-targeted smoking cessation interventions.

RECOMMENDATIONS FOR IMPROVING EQUITY IN NIH FUNDED RESEARCH

The SGMRO can help the NIH improve their workforce diversity and expand the equity focus of their research portfolio by advising them to increase investments in community-based participatory research. Participatory research teaches the skill sets, creates communities of practice, and democratizes the skills of science. Community-based participatory research requires long-term relationships, investments in knowledge sharing, and by empowering people, creates innovation that advances community health from the ground up.

²³ See, e.g., Marta Prandelli & Ines Testoni (2021) Inside the doctor's office. Talking about intersex with Italian health professionals, *Culture, Health & Sexuality*, 23:4, 484-499; Hegarty P, et al., Drawing the Line Between Essential and Nonessential Interventions on Intersex Characteristics With European Health Care Professionals. *Review of General Psychology*. 2021;25(1):101-114.

²⁴ See, e.g., Jenny Sperling (2021) Comprehensive sexual health education and intersex (in)visibility: an ethnographic exploration inside a California high school classroom, *Sex Education*, 21:5, 584-599; Tiffany Jones (2016) The needs of students with intersex variations, *Sex Education*, 16:6, 602-618.

²⁵ Fredriksen-Goldsen K, Kim H, Barkan S. (2012 January). Disability Among Lesbian, Gay, and Bisexual Adults: Disparities in Prevalence and Risk. *American Journal of Public Health*. 102(1): e16-e21.

²⁶ Mirbolouk M, Charckhchi P, Kianoush S, et al. (2018, October 2). Prevalence and Distribution of E-Cigarette Use Among U.S. Adults: Behavioral Risk Factor Surveillance System, 2016. *Annals of Internal Medicine*. 169(7): 429-438.

Make improvements to the NIH Workplace Climate and Harassment Survey (WCHS)

Research is needed to understand the experiences of SGM employees of NIH. The WCHS has collected valuable information on the experiences of SGM staff, and serves as a valuable example for other research institutions. However, the WCHS has not included any measure allowing the identification of NIH staff who are intersex or have variations in sex characteristics. With the last survey including 15,794 respondents, intersex staff may be a small population, but identifying them should be just as feasible as identifying transgender staff.²⁷ SGMRO should advise the NIH to revise WCHS to enable better consistent identification of transgender staff. However, NIH should avoid only measuring intersex as a response option for questions about gender identity or assigned sex.

Invest in continued, meaningful engagement with SGM communities

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.

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.²⁸

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.

Improving access of SGM communities to research is done to ensure voices are included and to position ourselves to partner on research opportunities. However, formally recognizing the need for support and infrastructure, and providing the necessary funding for them, is needed to reach the goal of more structured community engagement.

²⁷ National Institutes of Health, NIH Workplace Climate and Harassment Survey (WCHS), November 16, 2020, accessed via <https://diversity.nih.gov/building-evidence/harassment-survey>.

²⁸ Research America, U.S. Investments in Medical and Health Research and Development, 2018, accessed via https://www.researchamerica.org/sites/default/files/Policy_Advocacy/2013-2017InvestmentReportFall2018.pdf.

Including community members that are marginalized across multiple intersecting identities requires a supportive research environment. The NIH can improve the participation of SGM communities by providing supports through paying people for their time, paying for child-care and transportation. Building in flexibility and additional support can help build relationships and address socioeconomic barriers to participation in research. Community involvement thrives in more holistic healthcare and research environments that address multiple systems of oppression, which requires having a multitude of perspectives on research programs that involve SGM people.

NIH can improve participation of community members in research through intentional investment in community's capacity, including investments in education and professional development to support more community in leadership roles in health and research-related fields.

Recognize and reward community members' contributions to health care innovations

Community health centers or other community partners can be key to the research project and outcomes but are often not recognized – financially or in the research publication process – as an equal partner. 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.

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 support sustainable research programs.

Improve the translation of research outcomes into medical practice

Patients and research participants would benefit from more activities to communicate and implement the outcomes of research to the broader community. Lack of researcher communication, from recruitment to dissemination, is a barrier for research engagement by SGM people. Research participants often report that they cannot identify the benefits of participation in research projects. Additionally, many LGBTQIA+ people who participate in both social science and clinic research report feeling survey fatigue, in particular for persons who live at the intersection of multiple marginalized identities, for whom participating in research can be both a fraught and empowering activity.

Based on our experience, SGM research participants identify that they feel they are often the subjects of research, but not the beneficiaries of research. This can contribute to feelings of distrust around the purpose, quality, and results of research, harkening back to histories of medical exploitation. Because of these dangers, it is essential that research studies on LGBTQIA+ people include adequate funding for evaluation and implementation of research.

Invest in building capacity for SGM research participants

We recommend using approaches to research development that not only engage, but build capacity and invest in SGM people. The SGMRO can push the NIH to provide funding for programs that build capacity for developing research proposals to adequately compensate community members for their time, expertise, and emotional labor in addition to provision of stipends for transportation and writing.

Researchers must be intentional about building relationships with communities and working with community members throughout all stages of the research, from development of the research proposal to dissemination of the results, to application of research outcomes. Researchers should seek to partner with existing LGBTQIA+ organizations or groups with LGBTQIA+ leadership in order to ensure research goals are aligned with community needs that communities can derive the benefits from the research agenda.

Recommendations to achieve health research goals of LGBTQIA+ communities

More holistic approaches to health research that consider intersections of identities are needed. Future research should seek to engage multiple aspects of health and well-being. If research is disease-specific or population-focused, it should intentionally examine multiple mental, physical, spiritual, social, and other related factors while also accounting for structures and systems of power and oppression. Future research should build on existing analytic frameworks and theories that examine the root causes of health inequities.

Moreover, intentional efforts to understand and deconstruct the inherent power dynamics and inequities between SGM people and researchers is needed, especially if the researchers are not SGM. Provide funding to conduct thorough reviews of existing health literature, including scientific and academic publications, as well as community-developed resources and literature by and for SGM people and engage SGM people in appraising the quality and limitations of existing research, as well as translate existing high-impact research findings into accessible materials for providers and SGM communities.

We recommend supporting these methods of improving engagement with LGBTQIA+ people:

- a. Pay for monthly time commitments for community members participating in research,
- b. Create communities of care through hosting social events,
- c. Form smaller mentorship teams by research interest for more hands-on and relevant research training,
- d. Develop emergency funds for members who are experiencing acute crises such as loss of housing, food insecurity, or unexpected medical costs, and

- e. Invest in ongoing and meaningful opportunities for transgender and gender expansive people involved in community-engaged health research to convene, build networks, access training, and share skills, findings, and strategies.

RECOMMENDATIONS FOR IMPROVING ACCESS TO NIH-FUNDED RESEARCH OPPORTUNITIES FOR COMMUNITY-BASED ORGANIZATIONS

The following are opportunities for SGMRO to improve equity in community health research by increasing the capacity of community-based research organizations to develop and implement community-based participatory research programs:

- (1) There is inadequate funding for research training and mentorship to occur within community-based organizations rather than traditional academic environments. The SGMRO should encourage the NIH and other partners to 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 SGMRO should advise partners to create 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. 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.
- (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 SGMRO should partner with other federal organizations to create mechanisms to incentivize researchers to continue partnering with organizations to sustain the work done within research.
- (4) Currently, in research applications there is a narrow focus on individual investigators and their careers rather than on collaborative programs of research. We ask the SGMRO to recommend that federal partners institute research mechanisms that prioritize teams, coalitions, and organizations and broad programs of research. Team-based approaches

broaden the opportunity to invest in a diversity of sources of advancement and innovation in health research. Team-based research approaches incorporate multiple perspectives which helps ameliorate the effects of bias, encourages interdisciplinary research and finding holistic, practical applications of research findings.

(5) We ask the SGMRO to support partners in identifying resources to develop new, community-embedded centers of excellence and other programs including new funding opportunities to support non-academic research centers or collaborative networks of community-based organizations and funding a research network of community health centers and research hospitals to track an ongoing clinical cohort of SGM patients. This could be similar to the CFAR Network of Integrated Clinical Systems (CNICS) Research Network. It could allow us to better understand LGBTQIA+ health disparities, health care needs, and inform improvements to care. There are many opportunities for research that would benefit SGM patients with this kind of coordinated, collaborative approach.

(6) 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 ask the SGMRO to direct partners to create specific mechanisms or incentives for researchers, particularly from underrepresented backgrounds, to conduct research within community-based organizations.

(7) Part of the systematic under resourcing of community engagement in NIH-funded research is the inadequate resources for community-based organizations to establish appropriate Facilities & Administrative rates to support the development of research programs. We ask the SGMRO to recommend that the NIH 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 research programs.

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,

AIDS United, Washington, D.C.
Center for American Progress, Washington, DC
Fenway Health, Boston, MA
GLMA: Health Professionals Advancing LGBTQ Equality, Washington, DC
Howard Brown Health, Chicago, IL
interACT: Advocates for Intersex Youth, Sudbury, MA
Lyon-Martin Health Services, San Francisco, CA
National Black Justice Coalition, Tallahassee, FL
National Center for Transgender Equality, Washington, DC
Transhealth Northampton, Northampton, MA
Whitman-Walker Institute, Washington, DC