Summary of Public Comments

NIH FY 2016-2020

Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities

NATIONAL INSTITUTES OF HEALTH

SEXUAL & GENDER MINORITY RESEARCH OFFICE

SEXUAL & GENDER MINORITY RESEARCH COORDINATING COMMITTEE

NIH National Institutes of Health
Division of Program Coordination,
Planning, and Strategic Initiatives

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Introduction

In September 2015, the National Institutes of Health (NIH) released a *Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities (SGM)*. Included in this plan is information from substantive analysis and integration of portfolio analyses, community input, inter- and intra-agency collaborations, and recommendations from the NIH-commissioned Institute of Medicine report *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, which was released in 2011.

The NIH SGM Strategic Research Plan promotes and supports the advancement of basic, clinical, and behavioral and social sciences research to improve the health of people whose sexual orientations, gender identities/expressions, and/or reproductive development vary from traditional, societal, cultural, or physiological norms. In each of these areas, the NIH will coordinate with intramural researchers and extramural program directors to promote the advancement of SGM-focused research efforts.

The NIH anticipates that this 5-year plan, which covers the years 2016–2020, will provide a framework for progress in this area. Research that results from this plan will lay a foundation for improved health and well-being among a group of diverse SGM individuals whose health needs historically have received less attention from the research community.

About Public Comments

The public comments received regarding the Strategic Plan will be taken into consideration as the NIH seeks to implement its goals and objectives. The NIH sought input from researchers in academia and industry, health care professionals, patient advocates, health advocacy organizations, scientific and professional organizations, public agencies, and other interested members of the public. The following provides a summary of responses received regarding the Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities. Both observations and recommendations are included in this summary. Some comments concerned activities outside the purview of the mission of the NIH; these comments are included in this document. Forty-three submissions were collected in approximately 1 month in late 2015. Comments were received from nonprofit/community organizations (17), individuals (16), researchers/academic medical centers (6), and professional societies/public entities (4).

About the Summary

This report is divided into five sections, one for overarching comments on the NIH SGM Strategic Plan and one pertaining to each of the four strategic plan goals. When feasible, comments are represented as they were submitted to best capture their intent. A number of comments focused on general issues that transcend the four goals of the strategic plan and are highlighted in Table 1.

Overarching Observations and Recommendations

Health and well-being are broad concepts, and the comments received regarding the strategic plan reflected this breadth. A number of comments did not address a specific goal area, but rather spanned all the goals, or multiple goals. These comments are summarized below, and may be considered in light of the other goal areas or independently.

Table 1. Comments That Transcend the Goals of the Strategic Plan
Seek input from diverse SGM communities.
Disseminate findings widely and to appropriate audiences.
Need to capture the unique social relationships of SGM persons to identify explanatory variables that impact health.
Should take care to use language that portrays positive outcomes for proper care of transgender populations; this speaks to the benefits of hormonal transition therapy in enhancing self-esteem and preventing depression, high-risk behaviors, and suicide in adolescents and young adults.
Encourage the NIH to continue to fund trans-NIH SGM-related initiatives, such as the administrative supplements, and organize similar to the AIDS Clinical Trials Group.
Should designate SGM populations as a health disparity population (multiple respondents).
Represent the primary stakeholder, the patient, in research priorities and prevailing standards of care.
Address suicide prevention.
Oppose this program and spending, which is completely unnecessary at this time; let the private groups do the research.
Include children and adolescents.

Table 1. Comments That Transcend the Goals of the Strategic Plan (cont.)

Strengthen the NIH's commitment by working with key LGBT organizations and advocacy groups in conjunction with the existent outreach strategies outlined by the Health and Human Services LGBT Issues Coordinating Committee.

Address the needs of American Indians/Alaska Natives (AI/AN).

Revise the current definition of bisexual (to include behavioral and self-identified).

Include Two Spirit issues.

Include Pacific Islanders.

Assess insurance status where possible in each of its funded studies.

Include SGM in the nursing curriculum.

Diversify attention to the health needs of sexual and gender minority populations beyond HIV/AIDS, and reflect the true scope of health disparities for these groups.

Taking hormones and changing your appearance does not change your sexual being.

Update language to be more specific—gay men, lesbian women, bisexual women, bisexual men.

Seek specific representation from bisexually identified community leaders, researchers, and patients when developing committees to evaluate SGM inclusion at the NIH, developing SGM-related calls for proposals or funding announcements, and reviewing SGM grant proposals

Establish a community-based SGM research network.

Identify specific health needs of young people (SGM youth).

Include genderqueer, non-binary, and gender nonconforming persons.

Address intersex human rights.

Provide an overview of pre-exposure prophylaxis (PrEP).

Should not show preference for specific groups, such as LGBT, women, minorities, the disadvantaged, etc. Other areas of research deserve support, such as brain diseases, serious mental disorders, and addictions.

Consider sexual orientation in multiple dimensions and across time. Review the definition of the term "bisexual" to be more inclusive and not further a false binary notion of sexuality and gender. Suggested definition: "the capacity for experiencing physical, romantic, and/or sexual attraction to and/or engaging in sexual behavior with more than one sex or gender."

Goal One: Expand the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research

Goal one of the strategic plan aims to encourage investigators to conduct SGM research in priority areas, as identified by the Institute of Medicine report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* and NIH analyses of the current research portfolio in SGM health. Additionally, goal one also intends to promote the development and implementation of appropriate measures and methods to facilitate SGM-related research. Comments received related to goal one are highlighted in Table 2.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research	
General Research Recommendations and Observations	The NIH should support community-based participatory research that includes trusted local organizations to assist in the identification and recruitment of participants for studies. (multiple respondents)
	The NIH should prioritize research on Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) violence, negative health outcomes correlated with LGBTQ violence, and social determinants that may be risk factors or resilience factors for exposure to violence in LGBTQ populations, as well as effective LGBTQ violence prevention programs.
	Important to increase not only the number of awards in SGM health, but also the total proportion of NIH funding dedicated to SGM health.
	Incorporate a focus on health services research, including research looking at the effect of new payment and delivery system models on SGM and other marginalized populations.
	We strongly urge the NIH to prioritize research on sexual and reproductive health particularly in SGM populations.
	Set-aside funding should be provided for SGM research.
	Fund a research network of community health centers and research hospitals to track an ongoing clinical cohort of LGBT patients to improve understanding of LGBT health.
	Cultivate SGM-identified NIH leadership and intramural research.
	Research welcoming environment initiatives within the Primary Care Provider setting.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)

General Research Recommendations and Observations (cont.)	Encourage researchers to develop evaluations of culturally sensitive SGM-related trainings for researchers to measure the outcomes of such trainings, including behavior changes and competencies.
	Evaluate the impact of different types of support systems for isolated LGBT individuals, including individuals with diagnosed or undiagnosed mental illnesses.
	Research specific health needs of women and girls.
	Include Native Americans.
	Sexual and reproductive health, including exposure to, and representation in, comprehensive sex education— • Sexual behavior • Prevention of sexually transmitted infections, including HIV • Personal decision making with regard to the number and timing of pregnancies and births • Unintended pregnancy risk • Healthy pregnancies and births • Access to abortion care • Use of reproductive technology • Fertility and infertility • Policies and programs that support SGM individuals and couples.
	Behavioral health.
	Mental health/behavioral health.
	Resiliency factors.
	Sub-populations: AI/AN; Pacific Islanders; rural and frontier populations.
	Adult survivors of child abuse.
	Research and data on conversion therapy and family acceptance.
	Geography (urban, rural, suburban, remote).
	Health across the lifespan (and generationally, such as boomers, gen-exers, millennials, etc.).
	Research on housing (elderly, runaway, assisted, shelters, etc.) and housing discrimination.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)

General Research Recommendations and Observations (cont.)	Chronic disease and disability (in older populations, and including HIV).
	Race/ethnicity/culture/geography (intersectionality).
	Out-of-home youth (homeless, foster care, juvenile justice system, mental health facility, etc.).
	Evaluate the effectiveness of school-based interventions to support LGBT and questioning youth.
	Children of LGBT parents (discrimination, harassment, bullying, etc.).
	Race, ethnicity, and culture in LGBT youth.
	Family formation, parenting, and grandparenting.
	Family acceptance interventions.
	SGM persons with disabilities.
	Minority stress (stigma, prejudice, discrimination, and violence).
	Health services research • Insurance status and the impact of the Affordable Care Act (ACA) • Structure, organization, and cost of care • Access to care (considering discrimination, ignorance and maltreatment by health care professionals) • Impact of the ACA
	Violence in the LGBTQ community (intimate partner violence, sexual violence, and hate violence).
	Health impacts of sexual orientation and gender identity nondiscrimination laws and policies on LGBT health.
	Health impacts of extending nondiscrimination protections to all SGM groups for all health programs and activities funded to any extent by the Federal Government.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)	
Data Collection and Measurement	The NIH should promote best practices and standards for collecting and analyzing sexual orientation and gender identity (SOGI) data. Data for gay men and lesbians should not be lumped together, as this can obscure important differences between two distinct populations. The NIH should collect epidemiologic, demographic, and other foundational data to inform interventional research into SGM populations.
	The NIH should encourage researchers to collect data on social determinants of health for LGBTQ populations that may identify risk and resilience factors for exposure to violence.
	More and better data is critical.
	Guidelines on data collection, including analysis of sub-populations and research on disclosure of sensitive items.
	Collect both birth sex and current gender identity information through a two-part question.
	Should work with other public and private entities on demographic and health data collection.
	The NIH should take the lead on developing and standardizing a well-validated set of questions to be used in research for gathering SOGI information.
	The NIH should create consistency in grouping or categorizing sex and gender data across time, data systems, and the profusion of terms used for sex and gender identity.
	The NIH should enhance flexibility to accommodate many different existing data collection practices.
	The NIH should create a concise, feasible method of data collection that could be widely applied.
	The NIH should work to improve clarity in the meaning and comfort in the use of terms defining sex and gender.
	The NIH should collect data that enable people to see themselves in the response options.
	Need recruitment strategies specific to bisexual communities; use bi-inclusive language (same-sex or same-gender relationships vs. lesbian and gay).
	Select methods and measures for health equity research based on community input.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)

Transgender Health	Population-based, health systems-based, clinic-based, and venue-based (encourage the NIH to assemble a multisite cohort of 10,000-25,000 transgender individuals).
	Different delivery modes and schedules for hormonal therapy.
	Patient navigation methods and physician-decision algorithms.
	Use a biopsychosocial approach to adult development and quality of life of transgender and gender nonconforming people.
	The NIH should invest in areas where little research is available for specific SGM sub-populations at greatest risk of experiencing disparities, especially transgender populations (particularly transgender women of color who experience disproportionate rates of violence, incarceration, and HIV/AIDS), sexual minority women, racial and ethnic minorities, youth and elders, and persons with disabilities.
	Full histories of surgical procedures and details of past and current hormonal exposures.
	PrEP and other HIV prevention needs of transgender women.
	Access to and outcomes of surgery, facial reconstructive procedures, electrolysis, and augmentation mammoplasty.
	Therapies administered within and outside professional care settings and treatment received in the United States vs. abroad.
	Barriers to health care • Assess knowledge and sophistication of provider workforce and barriers to education. • Assess bias and other barriers to provider care, independent of knowledge. • Determine the degree to which third-party payer policies impede access to care and changes needed to overcome the financial barriers to care. • Evaluate other barriers, including stigma, mental health issues among patients, and socioeconomic issues that represent barriers to transgender individuals' receiving high-quality care.
	Gender identity development across the lifespan.
	Gender non-conforming youth.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)

Pre-pubertal youth	Prevalence and predictors of persistence among children with gender dysphoria.
	Examine outcomes of a gender-affirming model vs. other approaches to the care of pre-pubertal youth.
	Impact and implications of social transition in childhood and the impact of parental anxiety on decision making about early social transition.
Early pubertal youth	Optimal timing of intervention with puberty blockers.
	Effects of puberty blockade on mental and social health/behavior and its effect on adolescent risk-taking behaviors (including suicidality, substance use, and sexual activity).
	Impact and safety of puberty blockade on bone health, metabolic markers, brain development, and fertility.
	Efficacy of different modalities to suppress puberty; analogue implants, analogue injections, GnRH antagonists.
	Implications for future vaginoplasty and other surgical procedures in those blocked in early puberty.
Late pubertal/post-pubertal youth	Optimal timing of interventions, including cross-sex hormones and gender confirmation surgeries; discussing hormones in balanced terms, noting both side effects and positive effects.
	Impact and safety of cross-sex hormone use initiated in adolescence on metabolic markers, brain development, and fertility.
	Mental and social health of young people initiating cross-sex hormones in adolescence, including the effect on risk-taking behaviors, such as suicidality, substance use, and sexual activity.
	Impact of sex steroid exposure during puberty on the development of osteoporosis, and risk of breast or prostate cancer.
Bisexual Health	Mental health.
	Prioritize research on bisexual health and well-being.
	Intimate partner violence.
	Physical health and indicators of well-being.

Table 2. Comments on Expanding the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research (cont.)	
Bisexual Health	Unique "coming out" experiences.
	Bi-phobia and stigma and discrimination (from both heterosexuals and homosexuals)—double discrimination.
Disorders of Sex Development (DSD)/ Intersex Health	Long-term prospective and retrospective studies of sexual and reproductive function and quality of life in relation to early medical, surgical, and psychosocial factors.
	Mining new supplemental data sources that are emerging, which give narrative retrospective accounts of care and outcomes.
	Health outcomes research looking at children with atypical genitals who did not have early genital surgery.
	Research on the true incidence of tumors in children and adults with DSD.
	Improve clinical management of DSD over the life course.
	Literature reviews and analysis of existing research, including review by disinterested researchers.
	Psychological support for affected children and youth.
	Psychological support for parents and families.
	The impact of peer support on children with DSD and their families.
	Eliminate unnecessary genital/gonadal surgery.
	Offer families strategies or support for delaying gender assignment until child can participate in the decision.
	Increase psychosocial support for patients and families.
	Increase children's opportunities to participate in decisions about their care.
	Refer or increase patient/peer and family access to support groups.
	Eliminate unnecessary genital exams and photography.

Goal Two: Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research About SGM Health and Well-being

In addition to addressing priority areas of research in SGM health, the NIH also must ensure that barriers to advancing SGM health research are addressed. Better coordination of activities related to SGM health research within and throughout the NIH Institutes, Centers, and Offices will further highlight NIH's commitment to this area of research and facilitate its growth. Enabling applicants to understand the characteristics of successful applications and ensuring NIH review expertise in SGM health research may facilitate innovative and progressive work in the field to continue and expand as science necessitates. Respondents provided several comments on ways that the NIH can remove barriers that currently exist for those conducting SGM-related research. Comments received related to goal two are highlighted in Table 3.

Table 3. Comments on Removing Barriers to Planning, Conducting, and Reporting NIH-Supported Research About SGM Health and Well-being
Support the establishment of a Sexual and Gender Minority Research Office in the NIH Office of the Director.
Utilize existing cultural competency trainings for LGBT issues in health care settings; expand upon proven programs.
Support mentorship opportunities.
Ground research analyses in the poor manner in which queer and trans people have been treated by the medical and research establishment.
Support increased cultural/structural competency in NIH study sections.
Expand upon programs proven successful in training racial and ethnic minority researchers in SGM (including Two Spirit) health issues.
Encourage inclusion of qualified researchers who identify as SGM to ensure that the community has a voice in review panels and study sections.
We urge the NIH, researchers, and clinicians to partner with trusted local organizations, such as PROMO and SAGE of PROMO Fund, to assist in the identification and recruitment of participants for studies.
Effectiveness of LGBT cultural competency training.

Goal Three: Strengthen the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Well-being

Strengthening the community of researchers and scholars who conduct research relevant to SGM health and well-being has emerged as a high NIH priority. Bolstering the SGM research community will ensure that the NIH is well poised to support high-quality and innovative work in SGM health research, with a pool of research experts upon whom it can call for insight and perspectives specific to the field. Comments received related to goal three are highlighted in Table 4.

Table 4. Comments on Strengthening the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Well-being
Develop a cadre of trained researchers through the establishment of regionally based SGM Centers of Excellence.
Create a work environment that mentors and supports SGM employees across all stages of careers (within and outside the NIH).
Support the establishment of an SGM Health Research Working Group of the Council of Councils; urge the DPCPSI Director to ensure that the working group includes qualified researchers who also identify as SGM.
Encourage the NIH to develop state-of-the-science conferences around specific SGM-related topics.
Encourage the NIH to develop resources and training for executive-level leaders at universities, hospitals, and clinics to help generate buy-in from senior leaders who value and prioritize SGM-specific research.
The NIH should provide technical assistance to LGBTQ anti-violence organizations and marginalized LGBTQ researchers on successfully applying for funding for anti-violence research projects.
The NIH should collaborate with researchers from other systems—such as criminal justice, housing, labor, and human services—on LGBTQ communities' experiences of violence.
Seek out and support openly identified SGM researchers.
Promote an affirming work environment for SGM-identified employees.
Foster SGM mentorship and career development.
Routinely include SGM in the Enhancing the Diversity of the NIH-Funded Workforce Program.
The NIH should partner with behavioral and social sciences professional organizations to enhance investigator understanding of NIH funding mechanisms, review processes, and training opportunities, and should specify what disciplines are included in behavioral and social sciences, and specify what research can be done in life sciences, by discipline.

Goal Four: Evaluate Progress on Advancing SGM Research

During the implementation of this Strategic Plan, the NIH will develop an evaluation plan, and call upon experts to review the state-of-the-science and our progress toward meeting the outlined goals and objectives. Existing internal tracking tools will be updated to ensure that SGM tracking reports are accurate and complete, and to ensure that reporting is transparent and timely. Finally, the NIH will involve all of its Institutes, Centers, and Offices through the Sexual & Gender Minority Research Office and the NIH Sexual & Gender Minority Research Coordinating Committee to align the evaluation activities across the agency. Comments received related to goal four are highlighted in Table 5.

Table 5. Comments on Evaluating Progress on Advancing SGM Research
Efforts should be tracked and reported on annually (multiple respondents).
Conduct robust evaluation and assessment of any new engagement efforts (with advocacy groups and key LGBT organizations) to determine and document their effectiveness.
Use quantitative and qualitative measures.
Include strategies to increase not only the number of SGM-related awards, but also the total proportion of NIH funding dedicated to SGM health research. Establish mechanisms to regularly measure and report this increase.

The NIH will work across its Institutes, Centers, and Offices to ensure that the feedback summarized in this document from researchers, the nonprofit community, professional societies, and the general public is taken into consideration as it works to implement the four goals of its SGM Strategic Plan.