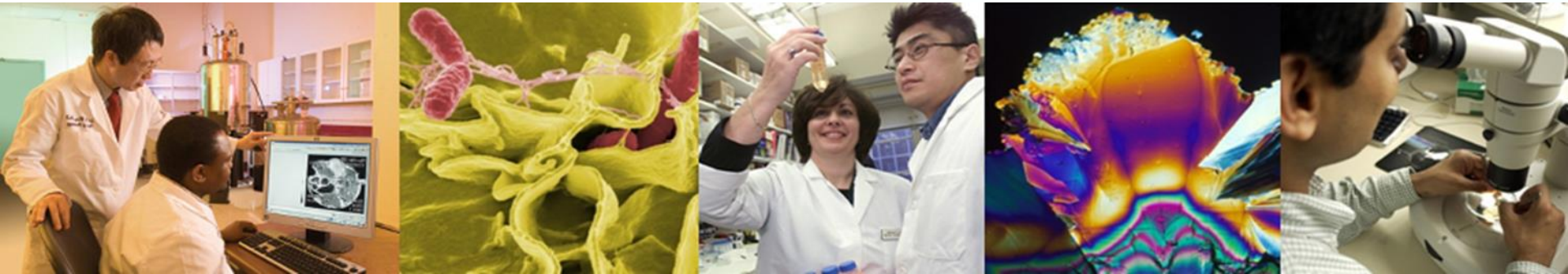


# Sexual and Gender Minority Research Activities at the NIH



**Karen L. Parker, PhD, MSW**

**Sexual and Gender Minority Research Office**

**Division of Program Coordination, Planning, and Strategic Initiatives**

**Office of the Director, NIH**

# Sexual and Gender Minority (SGM) Research at NIH

- Terminology and Context
- Institute of Medicine (IOM) Report
- NIH Response to the IOM Report
  - Research Coordinating Committee
  - Portfolio Analyses
  - Strategic Plan
- Development of Sexual and Gender Minority Research Office (SGMRO)
- Targeted Funding
- Next Steps
- Role of the Council of Councils



# SGM Definition

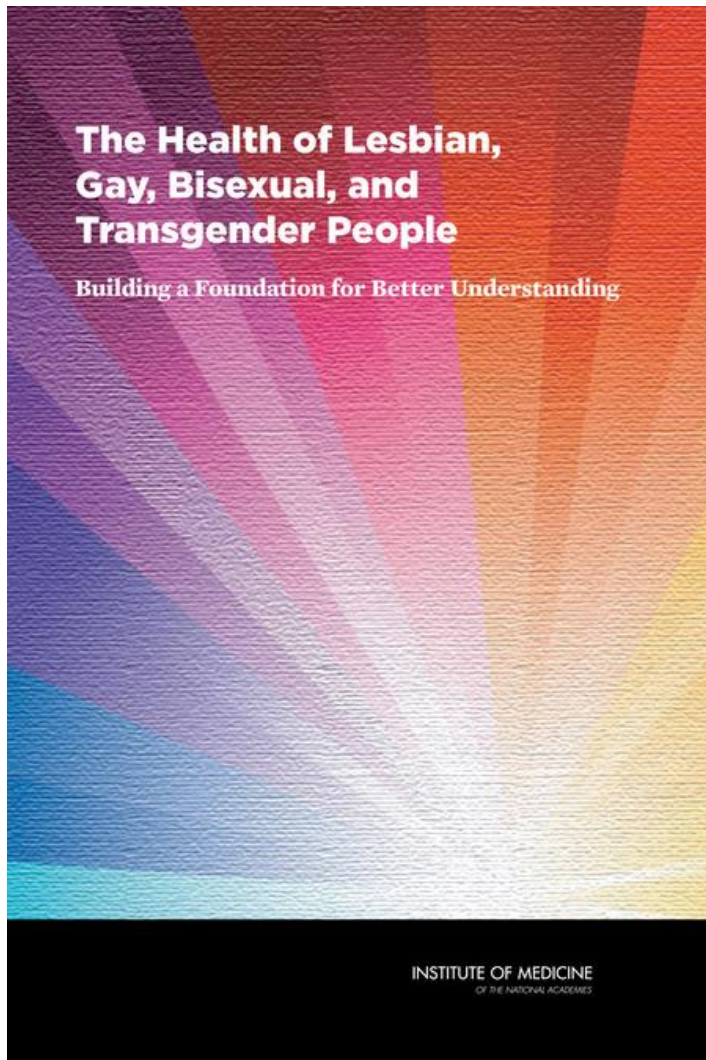
- **Sexual and/or Gender Minority** (SGM): people whose sexual orientations and/or gender identities/expressions, or reproductive development vary from traditional, societal, and/or cultural norms

# Importance of SGM Health and Research

- Contemporary health disparities based on sexual orientation and gender identity are rooted in and reflect the historical stigmatization of SGM populations.
- Heterosexual people (including many health care professionals), institutions, and systems function in a society that often stigmatizes SGMs.
- This has important implications for their ability to address the health needs of SGMs.<sup>1</sup>

<sup>1</sup> IOM (Institute of Medicine). 2011. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: The National Academies Press. Available at: <http://www.ncbi.nlm.nih.gov/books/NBK64806/>

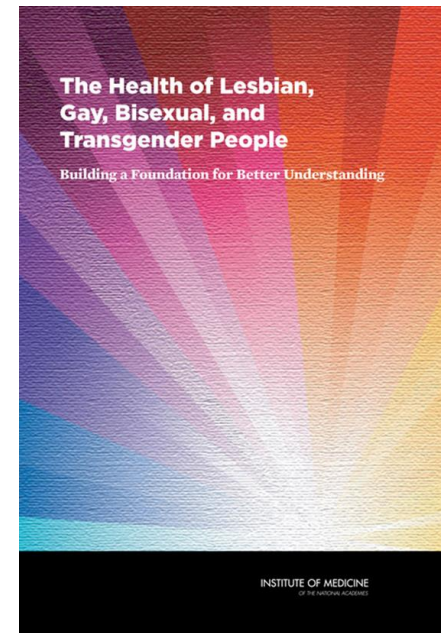
# The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding



- Commissioned by NIH in 2009, published in 2011
- Includes an extensive literature review of existing research on LGBT health
- First-ever comprehensive report on LGBT health
- Response to a call for a state of the science report and information on existing NIH LGBT research portfolio

# The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding, cont.

- The **2011 Institute of Medicine Report**<sup>1</sup> recommended a research agenda led by the NIH that includes the following areas:
  - Demographic research
  - Social influences on the lives of LGBT people that effect health
  - Inequities in health care
  - Intervention research
  - Transgender-specific health needs



# Intersectional Perspective

- **Intersectionality** (or intersectionalism) encompasses a set of foundational claims and organizing principles for understanding social inequality and its relationship to individuals' marginalized status based on such dimensions as race, ethnicity, and social class.<sup>1</sup>
- To fully understand SGM-related research and health needs it is necessary to examine the many factors that influence the health of SGM populations within the context of diversity:<sup>1</sup>
  - Racial
  - Ethnic
  - Socioeconomic
  - Geographic



# Report Recommendations

- For HHS
  - Collect sexual orientation and gender identity data (in federally funded surveys and in electronic health records)
- For NIH:
  - Implement a research agenda
  - Develop standardized gender identity measures
  - Support methodological research related to LGBT health
  - Create a comprehensive research training approach to strengthen LGBT health
  - Encourage grant applicants explicitly to address the inclusion or exclusion of sexual and gender minorities in other samples



# Research Coordinating Committee

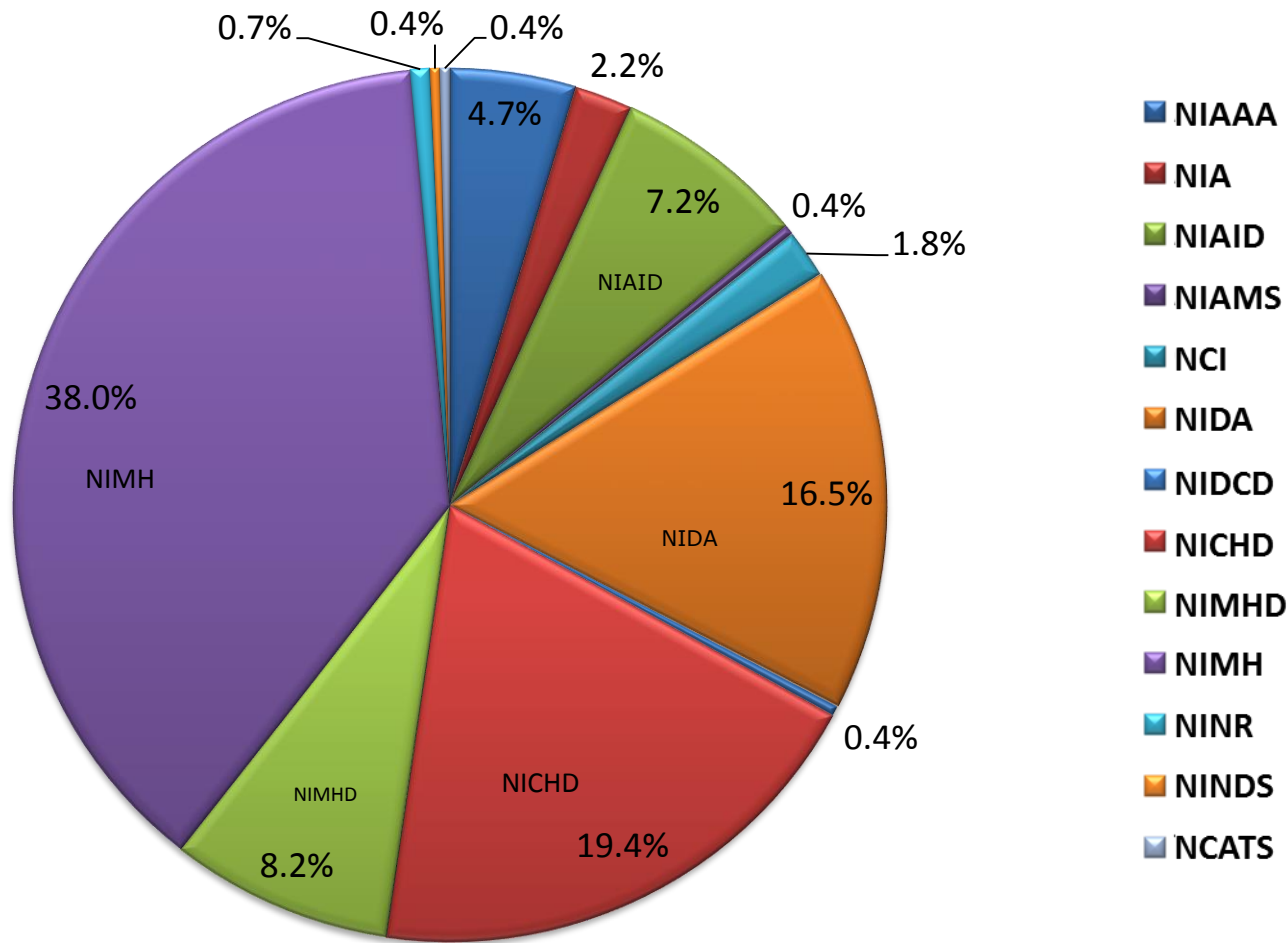
- Formed the LGBT Research Coordinating Committee (RCC) in March 2011 to consider possible NIH responses to IOM report
- Established the LGBTI RCC in 2013 as a standing forum for facilitating, developing, and coordinating activities related to LGBTI health research across the NIH and with other federal agencies
- Performed portfolio analyses of NIH-funded SGM health research (for FY 2010 and FY 2012, respectively)
- Changed name to Sexual and Gender Minority Research Coordinating Committee in 2015

# Findings from Portfolio Analyses

- Very little research focused on particular health needs of distinct SGM subgroups
- Many opportunities for multiple ICOs to create or further develop research and training programs
  - Examples: Cardiovascular, endocrine, neurological and/or cancer risks of long-term hormone use (transgender, intersex); minority stress; smoking; obesity; resiliency; needs across the life-span; depression; suicide
- Challenges related to methodological approaches and data collection needs

# FY 2012 Portfolio Analysis and Report

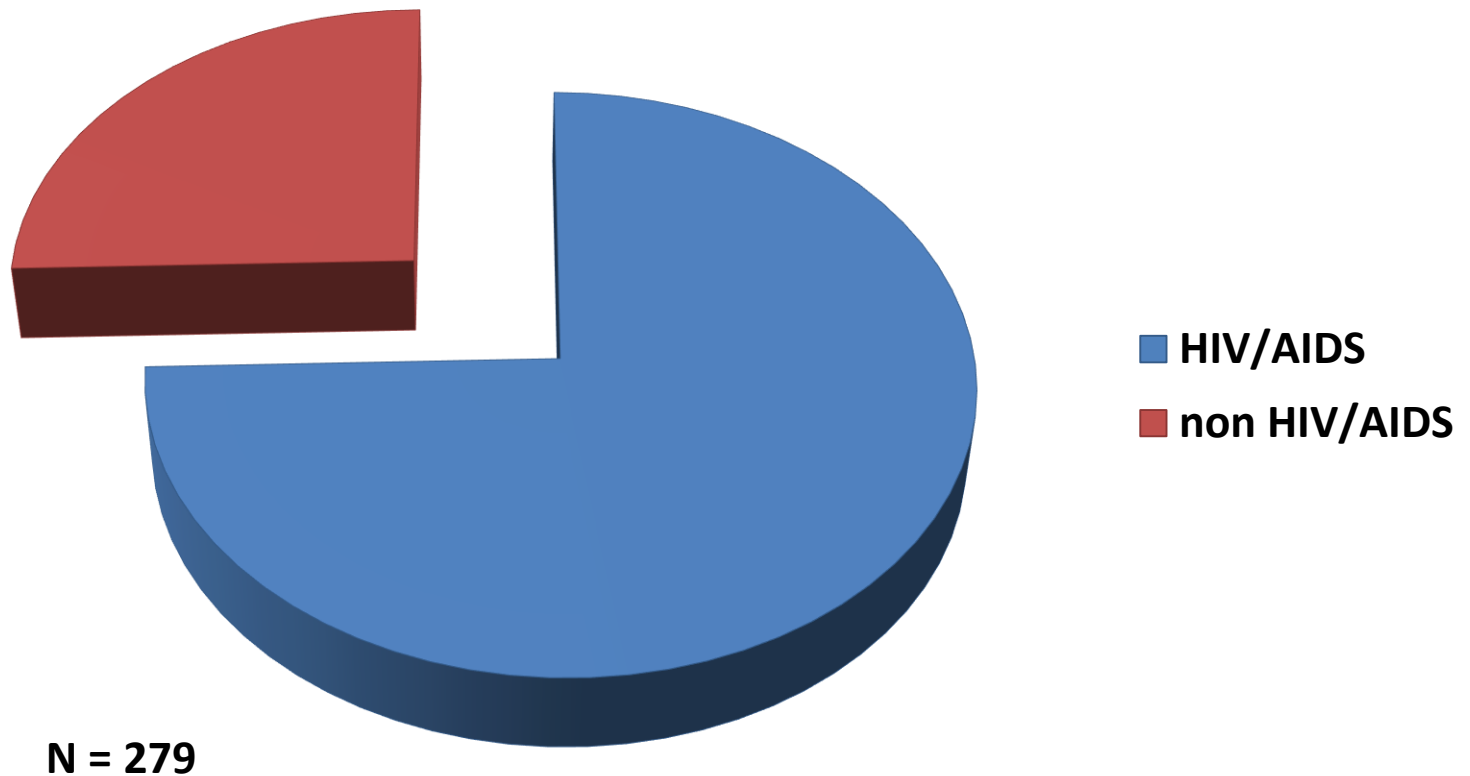
LGBTI Projects by NIH Institute/Center



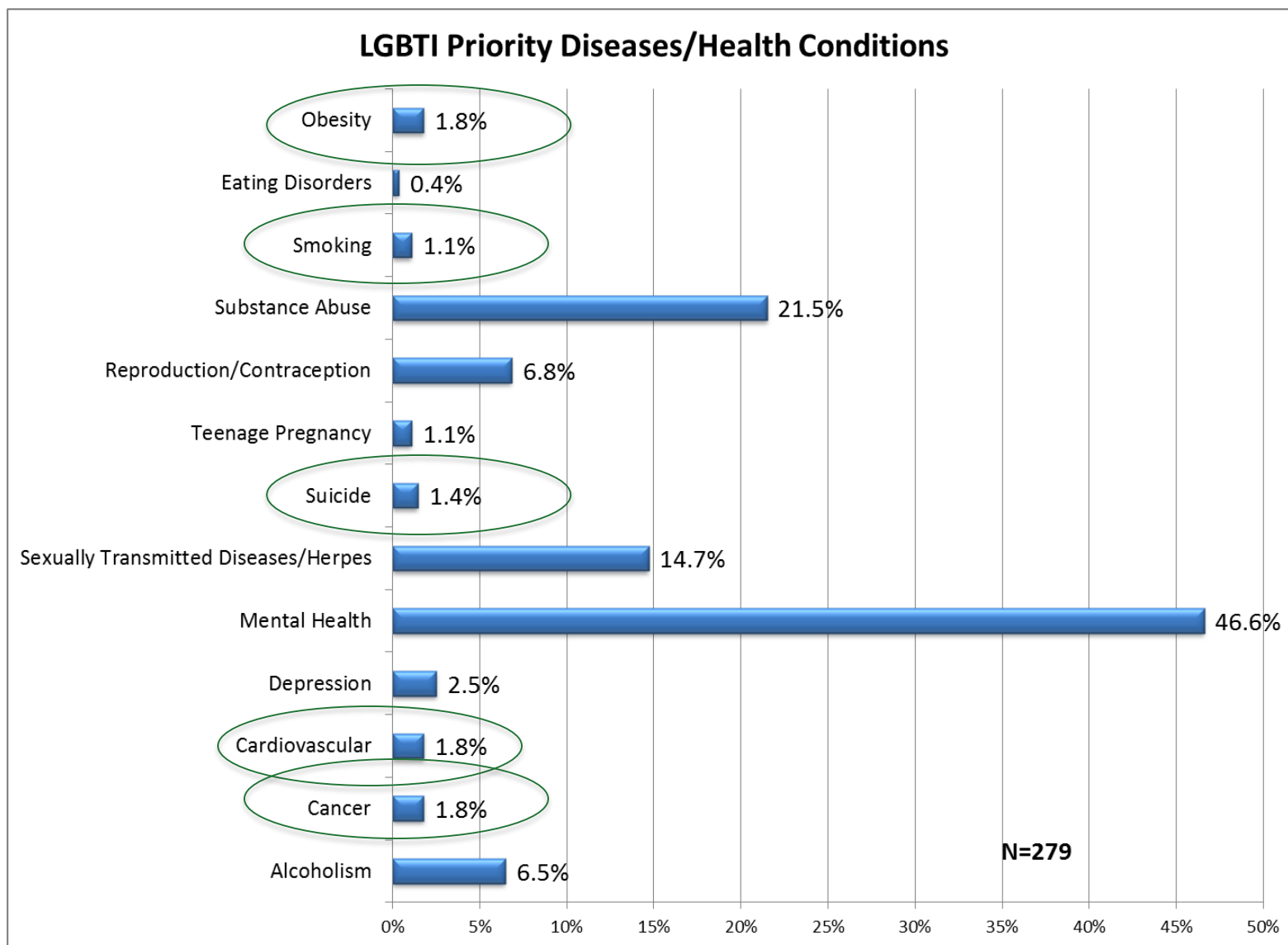
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# FY 2012 Portfolio Analysis and Report

## LGBTI HIV/AIDS vs Non-HIV/AIDS Projects

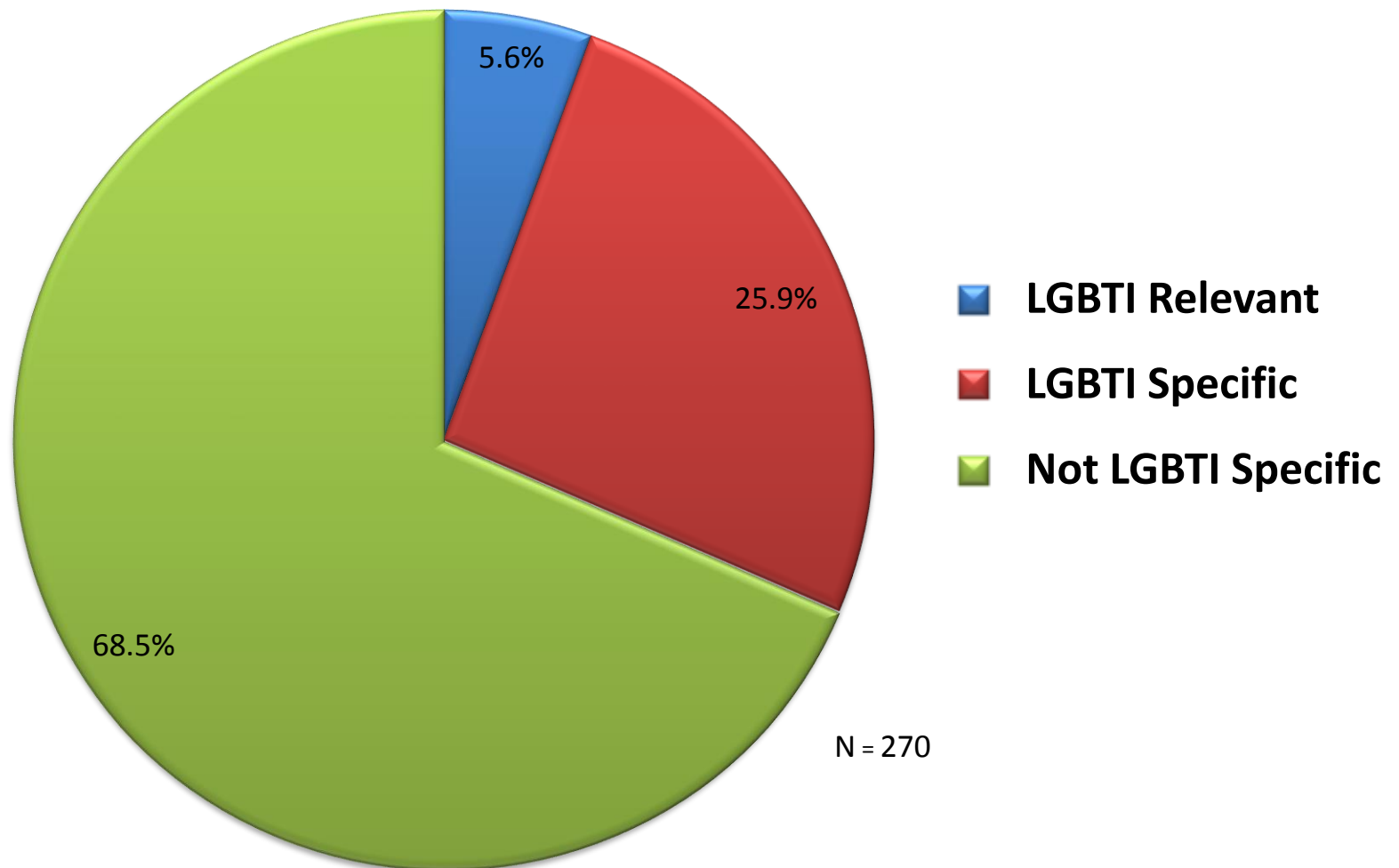


# FY 2012 Portfolio Analysis and Report



# FY 2012 Portfolio Analysis and Report

## LGBTI Projects Submitted to Targeted vs. Non-Targeted FOAs



# NIH LGBTI RCC

## *Outreach and Input Gathering*

- NIH Community
- Extramural Community
- Public



# NIH Strategic Plan to Advance Research on the Health and Wellbeing of Sexual and Gender Minorities

- Plan developed utilizing input from various stakeholders
- Finalized in September 2015
- Released for public comment in October 2015
  - Comments currently being summarized
  - Will be posted for public viewing
- Four Goal Areas and 11 Objectives
- Will serve as a blueprint for the Sexual and Gender Minority Research Office

# NIH SGM Strategic Plan

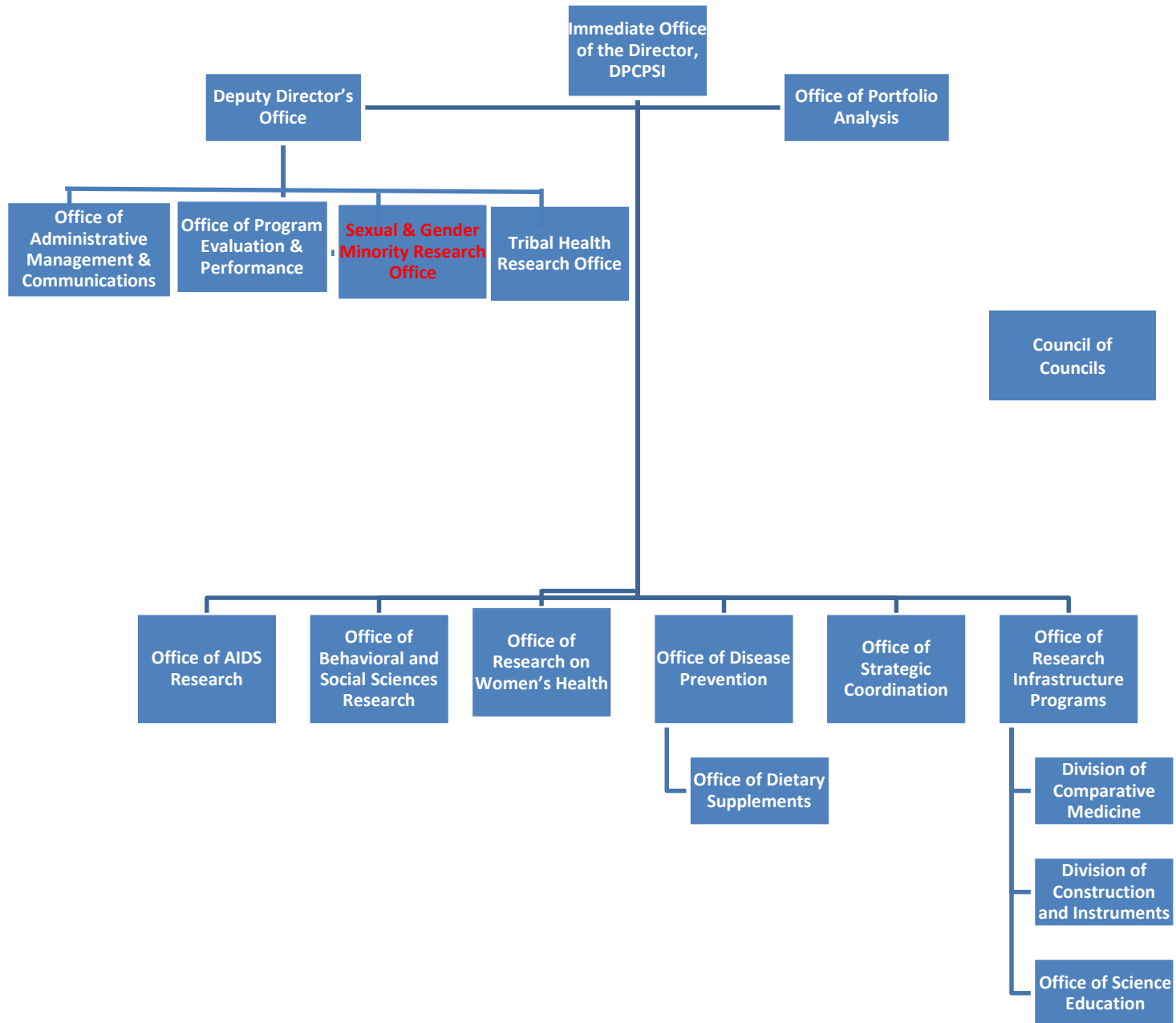
Approved by the NIH Director, 9/30/15

- Goal 1: Expand the Knowledge Base of SGM Health and Wellbeing Through NIH-Supported Research
- Goal 2: Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research about SGM Health and Well-being

# NIH SGM Strategic Plan

- Goal 3: Strengthen the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Wellbeing
  - Establish an NIH SGM Health Research Working Group of the NIH Council of Councils to provide subject matter expertise and strategic perspective for extramural and intramural NIH-funded SGM health and research-related efforts.
  
- Goal 4: Evaluate Progress on Advancing SGM Research

# DPCPSI Organizational Structure



# Sexual and Gender Minority Research Office

Established in late 2015, the role of the SGMRO is to:

- Coordinate SGM health research across NIH;
- Represent NIH on trans-NIH activities focused on SGM research;
- Coordinate and convene conferences and workshops to inform priority setting and research activities;
- Collaborate with NIH Institutes and Centers on development of SGM health research reports;
- Manage information dissemination related to SGM research; and
- Work to leverage resources and/or develop initiatives to support SGM health research.

# **Administrative Supplements for Research on Sexual and Gender Minority Populations**

- Released in August 2015
- Closed in November 2015
- 35 applications
- 10 ICs represented
- Funding to commence in summer 2016

# Other Recent Funding Opportunity Announcements

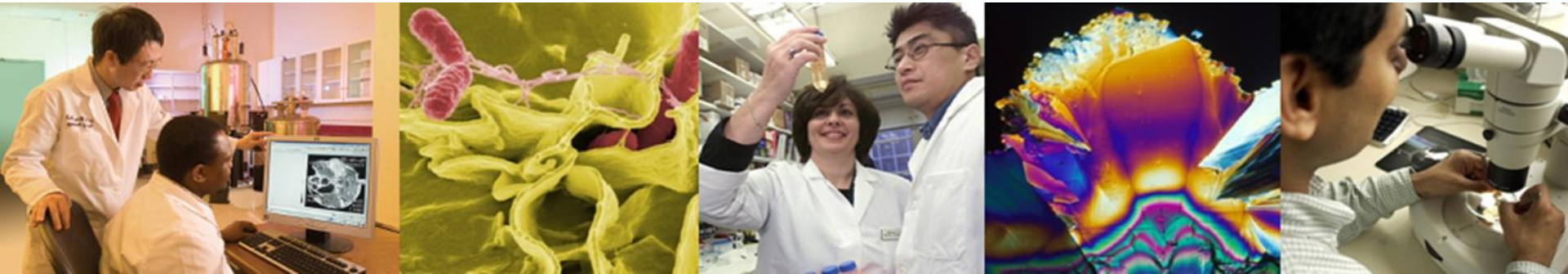
- Multidisciplinary Approaches for Developmental Research with Individuals with Disorders of Sex Development ([RFA-HD-16-021](#))
- Behavioral Interventions to Prevent HIV in Diverse Adolescent Men Who Have Sex with Men ([RFA-MD-15-012](#))
- The Health of Sexual and Gender Minority Populations ([PA-15-261](#))
- Seek, Test, Treat and Retain for Youth and Young Adults Living with or at High Risk for Acquiring HIV ([RFA-DA-15-019](#))



## Next Steps

- Update Portfolio Analysis with 2015 data
- Re-convene the SGM RCC with an updated charge
- Explore new opportunities for research collaborations
- Implement the goals of the Strategic Plan

# Sexual and Gender Minority (SGM) Research Working Group of the Council of Councils



**James M. Anderson, MD, PhD**  
**Director**

**Division of Program Coordination, Planning, and Strategic Initiatives**  
**Office of the Director, NIH**

# **SGM Research Coordinating Committee Charge**

The NIH Sexual and Gender Minority Research Coordinating Committee provides a trans-NIH forum for discussing the diverse health research issues of SGM communities and serves as a catalyst for developing additional research and research training initiatives in this area.

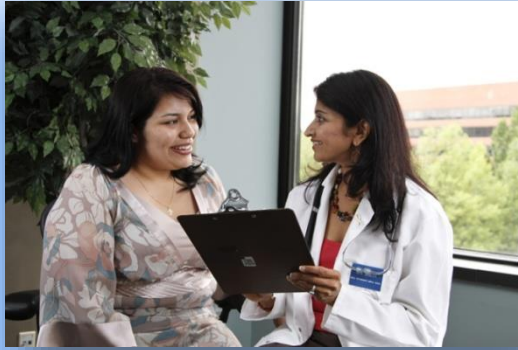
# **Council of Councils SGM Research Working Group Charge**

The Council of Councils Sexual and Gender Minority Research Working Group (SGMRWG) will advise the Council on activities of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) that relate to sexual and gender minority research. As a working group of the Council, the SGMRWG is charged with providing advice to the Council on the activities of the Sexual and Gender Minority Research Office (SGMRO).

# Council of Councils SGM Research Working Group Charge

In coordination with and in response to the DPCPSI and SGMRO Directors, the SGMRWG will provide scientific expertise and advice to the Council on:

- Opportunities for trans-NIH research collaborations;
- Strategies for increasing the number of SGM investigators and the number of investigators conducting SGM-relevant research;
- Approaches for optimizing outreach to the SGM research and stakeholder communities;
- Priorities for the most needed and promising areas of SGM-related research; and
- Other activities requested by DPCPSI.



# NIH...

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## Turning Discovery Into Health

