TELLING OUR STORIES
CATALYZING EFFORTS TO COLLECT SGM DATA

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WELCOME
Hannah Valantine, M.D.
Chief Officer, Scientific Workforce Diversity

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CATALYZING EFFORTS TO COLLECT SGM DATA

Sexual & Gender Minority Research @NIH
Karen L. Parker, Ph.D., M.S.W.

Sexual & Gender Minority Research Office

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NIH formed the LGBT Research Coordinating Committee (RCC) to consider possible NIH responses to Institute of Medicine report.

Performed portfolio analysis of NIH funded SGM health research (FY2010 data).

Established the LGBTI RCC as a standing forum for facilitating, developing, and coordinating activities related to LGBTI health research across the NIH & with other federal agencies.

Changed name to Sexual and Gender Minority Research Coordinating Committee; released the NIH SGM Strategic Plan Administrative Supplement.

Conducted subsequent portfolio analysis of NIH-funded SGM health research (FY 2012 data).

Sexual & Gender Minority Research Activities at NIH
SGM RESEARCH COORDINATING COMMITTEE CHARGE

The NIH Sexual & Gender Minority Research Coordinating Committee:

**Provides** a trans-NIH forum for discussing the diverse health research issues of SGM communities

**Serves** as a catalyst for developing additional research and research training initiatives in this area
NIH SGM STRATEGIC PLAN
TO ADVANCE RESEARCH ON THE HEALTH & WELL-BEING OF SEXUAL & GENDER MINORITIES

Plan developed utilizing input from various stakeholders

Finalized in Sept. 2015

Released for public comments in Oct. 2015
  Comments currently being summarized
  Summary of comments are posted on the SGMRO website

Four Goal Areas and 11 Objectives

Will serve as blueprint for Sexual and Gender Minority Research Office

Sexual & Gender Minority Research Activities at NIH
NIH STRATEGIC PLAN

GOAL 1

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

GOAL 2

Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research about SGM Health and Well-being

GOAL 3

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

GOAL 4

Evaluate Progress on Advancing SGM Research

Sexual & Gender Minority Research Activities at NIH
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
- **Convene** and coordinate 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
- **Work** to leverage resources and/or develop initiatives to support SGM health research

Sexual & Gender Minority Research Activities at NIH
DIVISION OF PROGRAM COORDINATION, PLANNING, AND STRATEGIC INITIATIVES (STRUCTURE)

Immediate Office of the Director
James M. Anderson, MD, PhD

Deputy Director’s Office
Robin I. Kawazoe

Office of Administrative Management & Communications
Ruby Akomeah, MS

Office of Program Evaluation & Performance
Rosanna Ng, MA

Sexual & Gender Minority Research Office

Tribal Health Research Office

Office of Portfolio Analysis
George Santangelo, PhD

Office of AIDS Research
Robert Eisinger, PhD (Acting)

Office of Behavioral and Social Sciences Research
Bill Riley, PhD

Office of Research on Women’s Health
Janine Clayton, MD

Office of Disease Prevention
David Murray, PhD

Office of Strategic Coordination
Betsy Wilder, PhD

Office of Dietary Supplements
Paul Coates, PhD

Office of Science Education
Tony Beck, PhD

Office of Research Infrastructure Programs
Franziska Grieder, DVM, PhD

Division of Comparative Medicine
Stephanie Murphy, DVM, PhD

Division of Construction and Instruments
Malgorzata Klosek, PhD

Division of Disease Prevention
David Murray, PhD

Division of Dietary Supplements
Paul Coates, PhD

Division of Science Education
Tony Beck, PhD

Division of Research Infrastructure Programs
Franziska Grieder, DVM, PhD

Division of Comparative Medicine
Stephanie Murphy, DVM, PhD

Division of Construction and Instruments
Malgorzata Klosek, PhD
RECENT FUNDING OPPORTUNITIES (EXAMPLES)

- 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 Young Adults Living with or at High Risk for Acquiring HIV (RFA-DA-15-019)
- Administrative Supplements for Research on Sexual and Gender Minority Populations
SGMRO NEXT STEPS

1. UPDATE
   - portfolio analysis with 2015 data

2. EXAMINE
   - new opportunities for collaborations

3. IMPLEMENT
   - the goals of the Strategic Plan

4. EXPLORE
   - opportunities for harmonizing research efforts across the Department
CONTACT INFORMATION

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klparker@mail.nih.gov

RYAN MAHON
ryan.mahon@mail.nih.gov

SEXUAL & GENDER MINORITY RESEARCH OFFICE
sgmhealthresearch@mail.nih.gov
TELLING OUR STORIES

CATALYZING EFFORTS TO COLLECT SGM DATA

The Power of Data in Advancing Equality
The Difference a Datum Makes

Naomi Goldberg
Policy & Research Director, Movement Advancement Project

#TELLINGOURSTORIES #FEDPRIDE2016
# The Power of Data In Advancing Equality

## Power of Data

1. **Who are LGBT people?**

2. **What do we know about LGBT people’s health?**

3. **What difference does data make?**
WHO ARE LGBT PEOPLE?

Diverse. Everywhere. More like you than you think.

The Power of Data In Advancing Equality
## PERCENT IDENTIFY AS LGBT

<table>
<thead>
<tr>
<th>Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>US Adults</td>
<td>3.4%</td>
</tr>
<tr>
<td>African Americans</td>
<td>4.6%</td>
</tr>
<tr>
<td>Asians</td>
<td>4.3%</td>
</tr>
<tr>
<td>Hispanics</td>
<td>4.0%</td>
</tr>
</tbody>
</table>

WITHIN LGBT POPULATION


The Power of Data In Advancing Equality
32% Children <18

16% Children <18

METRO AREAS WITH HIGHEST PERCENTAGE

WHAT DO WE KNOW ABOUT LGBT PEOPLE’S HEALTH

Health Disparities

The Power of Data In Advancing Equality
KEY HEALTH DISPARITIES

**Higher** rates of HIV for MSM and transgender people

**Higher** risk for and rates of certain kinds of cancer

**Higher** rates of mental health issues and suicidality

**Higher** rates of problematic substance use

The Power of Data In Advancing Equality
HEALTH DISPARITIES ARE LINKED TO SOCIAL EXPERIENCES

Legal discrimination

Social stigma, harassment, violence

Lack of competent programs and providers
WHAT DIFFERENCE DO DATA MAKE?

Can you cite life experience?

The Power of Data In Advancing Equality
COMMUNITY KNOWLEDGE MEETS RIGOROUS RESEARCH METHODS

The Power of Data In Advancing Equality
[F]or protecting the right to marry is that it **safeguards children & families**.... By giving recognition and legal structure to their parents’ relationship, **marriage allows children to understand** the integrity and closeness of their own family and its concord with other families in their community and in their daily lives.... Marriage also affords the **permanency and stability important to children’s best interests**.... Without the recognition, stability, and predictability marriage offers ... **children suffer the stigma** of knowing their **humiliate the children** of same-sex couples.”

- Justice Kennedy, *Obergefell v. Hodges*
How did We Get Here?

- Most people coming out, raising children
- Increased social science research about children raised by same-sex couples
- Growing number of foster and adoptive same-sex couples
- Census data provides “gold standard” as to how many children, where they live & more

The Power of Data In Advancing Equality
NTDS & TRANSGENDER EQUALITY

Education  Employment  Health  Family Life

Housing  Public Accommodations  Identity Documents

Police & Incarceration

The Power of Data In Advancing Equality
CONTACT INFORMATION

NAOMI GOLDBERG
naomi@lgbtmap.org

MOVEMENT ADVANCEMENT PROJECT
www.lgbtmap.org

The Power of Data In Advancing Equality
TELLING OUR STORIES
CATALYZING EFFORTS TO COLLECT SGM DATA

Stuart Michaels, Ph.D.
Sr. Research Scientist, NORC @ University of Chicago

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OVERVIEW

Brief History
of Surveys to measure LGBT population

Dimensions
of Sexual Orientation & Gender Identity

National Surveys
of Sexual Orientation & Gender Identity in the U.S.

LOOKING FORWARD

Data on LGBT Populations in National Surveys
HISTORY POPULATION SURVEYS TO MEASURE LGB POPULATION & POLITICAL CONTEXT

- **Early 20th century gay rights movement in German/legal reform:** Hirschfeld 1903 (first mail surveys)
- **Sexual Behavior/Marriage:** Kinsey Reports 1948 & 1953
- **Sexual revolution:** Kinsey Institute 1980
- **HHIV/AIDS:** GSS 1988 & NHSLS 1992
- **Sexual & Reproductive Health:** NSFG
- **LGBT health disparity:** NHIS 2013

Data on LGBT Populations in National Surveys
SEXUAL ORIENTATION AS A MULTI-DIMENSIONAL CONSTRUCT: SEXUAL BEHAVIOR, ATTRACTION & IDENTITY

Data on LGBT Populations in National Surveys
Questions about gender variance, identity, transgender are only recently emerging and have not been included in any federally funded nationally representative surveys.

No consensus on dimensions & measures

- Sex at birth vs. Current gender identity
- Gender Expression (masculinity/femininity)
- Transgender Identity

Like sexuality these are inter-related but non equivalent.
## Major National Surveys with LGBT Items

<table>
<thead>
<tr>
<th>Study Name</th>
<th>Official Acronym</th>
<th>Study Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Community Survey</td>
<td>ACS</td>
<td>census.gov/acs</td>
</tr>
<tr>
<td>National Longitudinal Study of Adolescent to Adult Health</td>
<td>Add Health</td>
<td>cpc.unc.edu/projects/addhealth</td>
</tr>
<tr>
<td>Behavioral Risk Factor Surveillance System</td>
<td>BRFSS</td>
<td>cdc.gov/brfss</td>
</tr>
<tr>
<td>United States Census</td>
<td>US CENSUS</td>
<td>census.gov</td>
</tr>
<tr>
<td>Current Population Survey</td>
<td>CPS</td>
<td>census.gov/cps/</td>
</tr>
<tr>
<td>General Social Survey</td>
<td>GSS</td>
<td>norc.uchicago.edu/GSS+Website/</td>
</tr>
<tr>
<td>National Health &amp; Nutrition Examination Survey</td>
<td>NHANES</td>
<td>cdc.gov/nchs/nhanes.htm</td>
</tr>
<tr>
<td>National Health Interview Survey</td>
<td>NHIS</td>
<td>cdc.gov/nchs/nhis.htm</td>
</tr>
<tr>
<td>National Survey on Drug Use and Health</td>
<td>NSDUH</td>
<td>oas.samhsa.gov/nsduh.htm</td>
</tr>
<tr>
<td>National Survey of Family Growth</td>
<td>NSFG</td>
<td>cdc.gov/nchs/nsfg.htm</td>
</tr>
<tr>
<td>Youth Risk Behavior Surveillance System</td>
<td>YRBSS</td>
<td>cdc.gov/HealthyYouth/yrbs/</td>
</tr>
</tbody>
</table>

Data on LGBT Populations in National Surveys
## LGBT Items in Surveys, Year, Age Range, Sample Size

<table>
<thead>
<tr>
<th>Study</th>
<th>Sexual Orientation/Gender Identity Measures</th>
<th>Analytic Details of Measure(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sexual Behavior</td>
<td>Sexual Identity</td>
</tr>
<tr>
<td>GSS</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>NSDUH</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>NHANES</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>ACS</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>YRBSS</td>
<td>X*</td>
<td>X*</td>
</tr>
<tr>
<td>NSFG</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Add Health</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>CPS</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>US CENSUS</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>NHIS</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Data on LGBT Populations in National Surveys
SEXUAL IDENTITY QUESTIONS FROM NHIS 2013

Which of the following best represents how you think of yourself?

- LESBIAN or GAY
- SOMETHING ELSE
- STRAIGHT, that is, not lesbian or gay
- I DON’T KNOW THE ANSWER
- BISEXUAL
- REFUSED

Data on LGBT Populations in National Surveys
COMPARISON OF SEXUAL IDENTITY IN NHIS & NHANES
(18-59 years olds)

Data on LGBT Populations in National Surveys
PERCENT SAME-SEX PARTNERS EVER FOR MEN & WOMEN
(18-44 in Selected U.S. National Survey)

GSSS – General Social Survey
NHSLS – National Health and Social Life Survey
NSFG – National Survey of Family Growth
Population research on sexuality and gender identity evolves in response to societal changes.

Research questions and concepts change over time.

Resources, ability, and willingness to do research evolve.

The emergence of LGBT social identities and movement affects the ability and willingness of funders, researchers, and respondents to ask and answer questions.

Expansion in the number and size of probability surveys that include questions on LGB(T) allowing us to address new questions about correlates, outcomes, and disparities.

Next Frontier: Inclusion of Gender Identity/Expression, Transgender.

Data on LGBT Populations in National Surveys.
CONTACT INFORMATION

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NORC @ the University of Chicago
www.norc.org

Data on LGBT Populations in National Surveys
Gay-rights groups dispute federal survey’s estimate of population

Gay-rights activists are distressed over the results of the first large-scale federal survey measuring sexual orientation in the United States, in which it reported in July that less than 2 percent of the population identifies as gay, lesbian or bisexual.

They contend it is a gross undercount and are particularly upset because they worked for years to get sexual orientation added to the 57-year-old National Health Interview Survey (NHIS), the government’s premier measure of Americans’ health statuses and behaviors. Now, the activists worry that the results will reduce the urgency of their causes and give fodder to their political foes.
# Gender Identity: The “Two-Step” Approach

<table>
<thead>
<tr>
<th>Assigned Sex at Birth</th>
<th>What sex were you assigned at birth, on your original birth certificate?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td></td>
<td>Female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current Gender Identity</th>
<th>How do you describe yourself? (check one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Transgender</td>
</tr>
<tr>
<td>Female</td>
<td>Do not identify as female, male, or transgender</td>
</tr>
</tbody>
</table>

Data on LGBT Populations in National Surveys
**Gallup**

Data on LGBT Populations in National Surveys

---

**Do you, personally, identify as lesbian, gay, bisexual, or transgender?**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>DK/Ref</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Men</td>
<td>3.3</td>
<td>92.5</td>
<td>4.2</td>
</tr>
<tr>
<td>Women</td>
<td>3.6</td>
<td>91.8</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Gallup Daily tracking
June 1-Sept. 30, 2012

GALLUP
SAME-SEX EXPERIENCE, ATTRACTION, IDENTITY AMONG U.S. WOMEN 18-44 NSFG 2006-2010

Data on LGBT Populations in National Surveys

Based on women who report any same sex partners, attraction, or gay/bisexual identity 21.1% of 9,964 women 18-44
Transgender Health Research: What’s Next

Jody L. Herman, Ph.D.
Scholar of Public Policy, The Williams Institute

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STATES THAT INTRODUCED ANTI-TRANS LEGISLATION IN CURRENT LEGISLATIVE SESSION

Transgender Population (ages 13 and up) Estimates
889 - 49,172
BATHROOMS & SAFETY CONCERNS

TRANS PEOPLE ARE AT RISK

- 70% Any Problem
- 18% Denied Access
- 68% Verbally Harassed
- 9% Physically Assaulted

Transgender Health: What’s Next
MOVING TRANS HEALTH RESEARCH FORWARD

2015 Trans Survey

3 Current Williams Institute Projects Advance SOGI Data Collection
- California Health Interview Survey
- Generations
- TransPop: Transgender Populations Health Survey

MORE DATA IS NEEDED

Administrative Data / EHRs

Transgender Health: What’s Next
2015 U.S. TRANS SURVEY

U.S. Trans Survey

Transgender Health: What’s Next
2015 U.S. TRANS SURVEY

Fielded
August & September 2015

Final Sample
27,715

35% Non-binary Genderqueer

Health Measures
- Health Insurance and health care access
- Kessler 6 Psychological Distress Scale
- Suicidal Thoughts & Behaviors (NSDUH)
- Substance Use (NSDUH)

Findings published late Summer 2016

Transgender Health: What’s Next
CALIFORNIA HEALTH INTERVIEW SURVEY

Large Health Survey
40k Adults
8k Youth

Two-Year Cycle
2015-2016

Demographics & Health Indicators/Outcomes

Sexual Orientation Measures
since 2001

Gender Identity Measures
Pilot Tested (Fall 2014)
Selected two-step measure based on pilot
Included in 2015-2016 cycle

www.healthpolicy.ucla.edu/chis

Transgender Health: What’s Next
The **Generations** study is the first long-term, five year study to examine the health and well-being across three generations of lesbians, gay men, and bisexuals (LGB). The study explores identity, stress, health outcomes, and health care and services utilization among LGBs in three generations of adults who came of age at different historical contexts.

The study is supported by the National Institute of Health, Office of Social and Behavioral Science and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (R01HD078526).
The study is supported by the National Institute of Health, Office of Social and Behavioral Science and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (R01HD078526).
ADMINISTRATIVE DATA / EHRs

Clinical Samples/Health Records

- Nested Matched Pairs designed at Fenway (S. Reisner, J. White J. Bradford, et al)
- Veterans Health Administration (G. Brown, J. Shipherd, J. Blosnich, et al)

Social Security Records

(B. Harris)

Medicare Records

(C. Haffer)

Electronic Health Records

(HHS Meaningful Use)
Catalyzing Efforts to Collect SGM Data
a Bureau of Labor Statistics Perspective

Julie Hatch Maxfield
Assistant Commissioner for Current Employment Analysis, Bureau of Labor Statistics

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DATA-DRIVEN DECISION MAKING

STRATEGIC OBJECTIVE
Support effective, data-driven decision-making and encourage transparency through intelligent gathering, analysis, sharing, use, and dissemination of information.

www.performance.gov

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
TYPES OF BLS SURVEYS

ESTABLISHMENT
(employer based)

by Guilhem Vellut

HOUSEHOLD
(people based)

by Jason Pratt

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
### CURRENT SURVEY POPULATION OVERVIEW

<table>
<thead>
<tr>
<th>SCOPE</th>
<th>PEOPLE AGED 16+ WHO RESIDE IN THE US</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAMPLE</td>
<td>60,000 HOUSEHOLDS</td>
</tr>
<tr>
<td>DATA COLLECTION</td>
<td>CENSUS BUREAU, IN-PERSON, PROXY</td>
</tr>
<tr>
<td>REFERENCE PERIOD</td>
<td>WEEK THAT INCLUDES THE 12TH</td>
</tr>
<tr>
<td>MAIN PURPOSE</td>
<td>DETERMINING LABOR FORCE STATUS</td>
</tr>
<tr>
<td></td>
<td>EMPLOYED</td>
</tr>
<tr>
<td></td>
<td>UNEMPLOYED</td>
</tr>
<tr>
<td></td>
<td>NOT IN THE LABOR FORCE</td>
</tr>
</tbody>
</table>
Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
Interviewers provided flash cards

Asked during 1st month’s meeting

No data available (yet)

Large error measures

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
**How Do Questions Get Added?**

<table>
<thead>
<tr>
<th>Identified potential need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cogitative tested</td>
</tr>
<tr>
<td>Do respondents understand what we are asking?</td>
</tr>
<tr>
<td>Literature search/subject matter expert</td>
</tr>
<tr>
<td>Respondent burden</td>
</tr>
<tr>
<td>Fully specified</td>
</tr>
<tr>
<td>Are we asking what we think we are asking?</td>
</tr>
<tr>
<td>Response rate</td>
</tr>
<tr>
<td>Federal Register Notice/OMB approval</td>
</tr>
</tbody>
</table>

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
Cognitive Interviews

Do respondents understand the questions?

Thoughts on privacy and sensitivity

Answer for themselves and all other members of their household

A subset of interviews will be member of the same household
  Compare answers

English only (to start)
Gender Identity | Transgender Populations

Cogitative Interviews

Focus Groups

4 cities (1 in DC, others mix of city/rural)

How do transgender respondents identify themselves? before/during/after transition

Important to gain understanding of transgender experience

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
GOALS OF TESTING SOGI QUESTIONS

Feasibility of adding questions to CPS
- Household based
- Proxy respondents
- Designed to capture labor market status

If preliminary conclusion is promising
- Identify next steps

Report expected in about one year

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
CONTACT INFORMATION

CPS Info Line

www.bls.gov/bls
202.691.6378
cpsinfo@bls.gov

CPS public use
micro data files

http://www.census.gov/cps/data

Catalyzing Efforts to Collect SGM Data: A Bureau of Labor Statistics Perspective
TELLING OUR STORIES
CATALYZING EFFORTS TO COLLECT SGM DATA

UPCOMING EVENTS

Fostering an Inviting Workplace for Transgender & Gender Nonconforming Employees
14 June 2016 | Building 31, C-Wing Room 7
1:00PM – 2:30PM
register at: edi.nih.gov/training/upcoming-training

Health Care & Research for the Transgender Community
30 June 2016 | Masur Auditorium, Building 10
10:00AM – 11:30AM
edi.nih.gov/pride

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