



TELLING OUR
STORIES
CATALYZING EFORTS
TO COLLECT SGM DATA

#TELLINGOURSTORIES #FEDPRIDE2016



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WELCOME

Hannah Valentine, M.D.

Chief Officer, Scientific Workforce Diversity

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TELLING OUR STORIES

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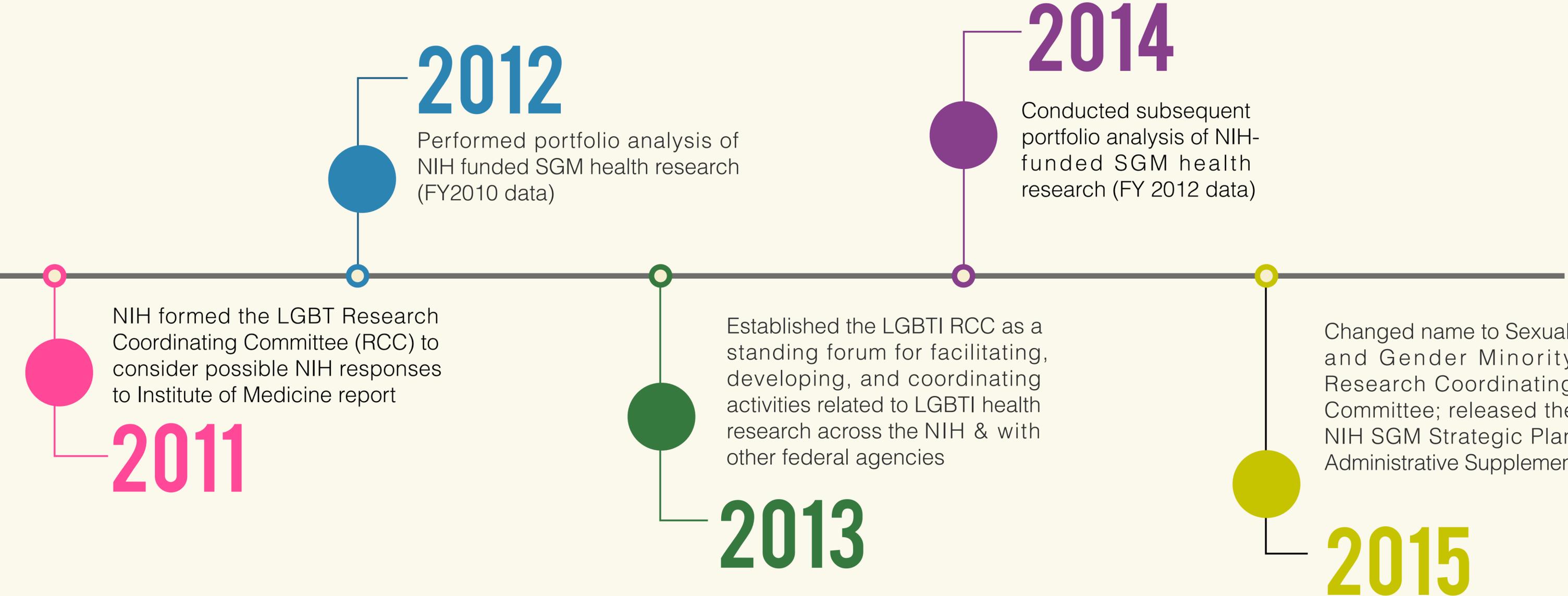
Sexual & Gender Minority Research @NIH

Karen L. Parker, Ph.D., M.S.W.

Sexual & Gender Minority Research Office

#TELLINGOURSTORIES #FEDPRIDE2016

SGM RESEARCH COORDINATING COMMITTEE TIMELINE



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

Four Goal Areas and 11 Objectives

Finalized in Sept. 2015

Will **serve** as blueprint for Sexual and Gender Minority Research Office

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

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 OFFICE

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

Coordinate SGM health research across NIH

Collaborate with NIH Institutes and Centers on development of SGM health research reports

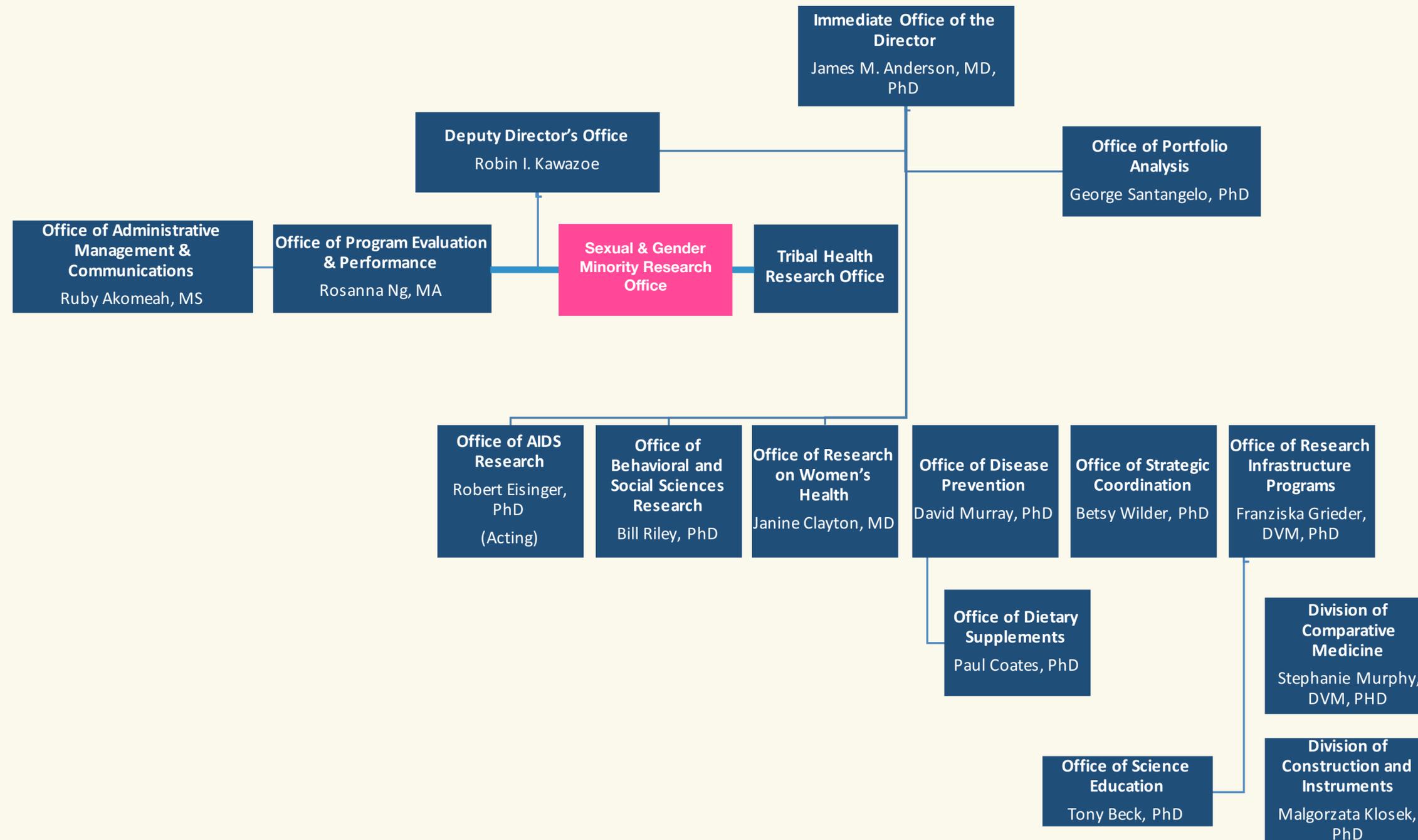
Represent NIH on trans-NIH activities focused on SGM research

Manage information dissemination related to SGM research

Convene and coordinate conferences and workshops to inform priority setting and research activities

Work to leverage resources and/or develop initiatives to support SGM health research

DIVISION OF PROGRAM COORDINATION, PLANNING, AND STRATEGIC INITIATIVES (STRUCTURE)



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 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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**SEXUAL & GENDER MINORITY
RESEARCH OFFICE**

sgmhealthresearch@mail.nih.gov

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

Naomi Goldberg

Policy & Research Director, Movement Advancement Project

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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.**

PERCENT IDENTIFY AS LGBT

3.4%

US Adults

4.6%

**African
Americans**

4.3%

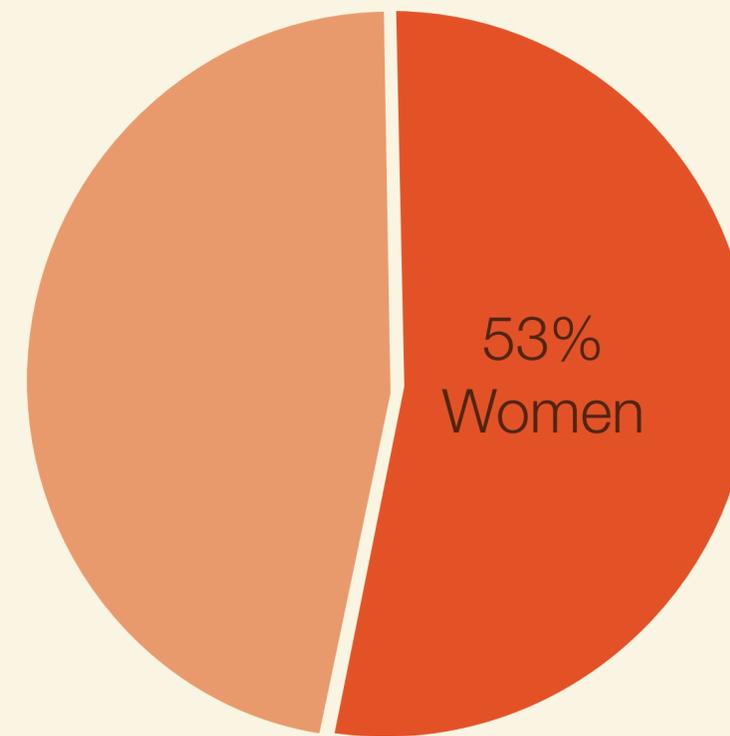
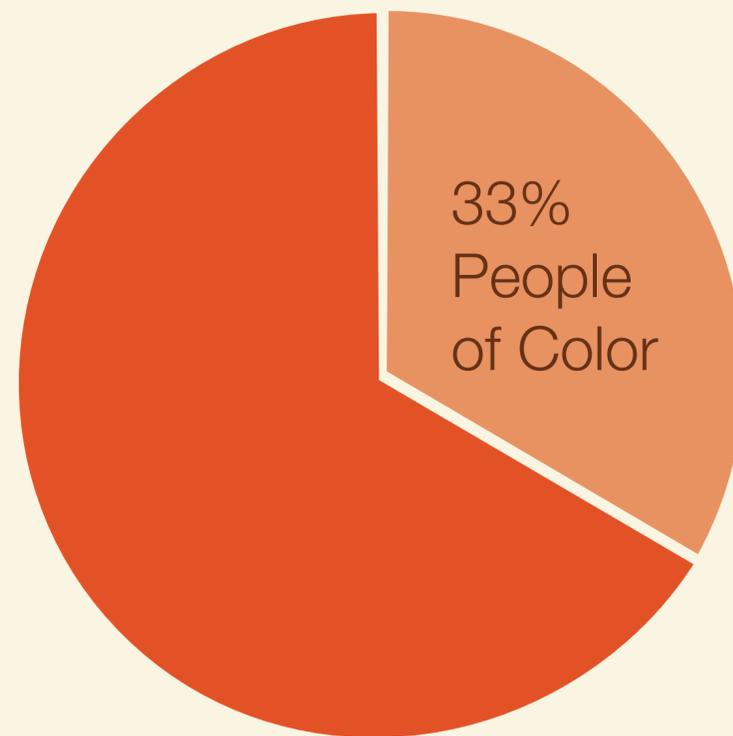
Asians

4.0%

Hispanics

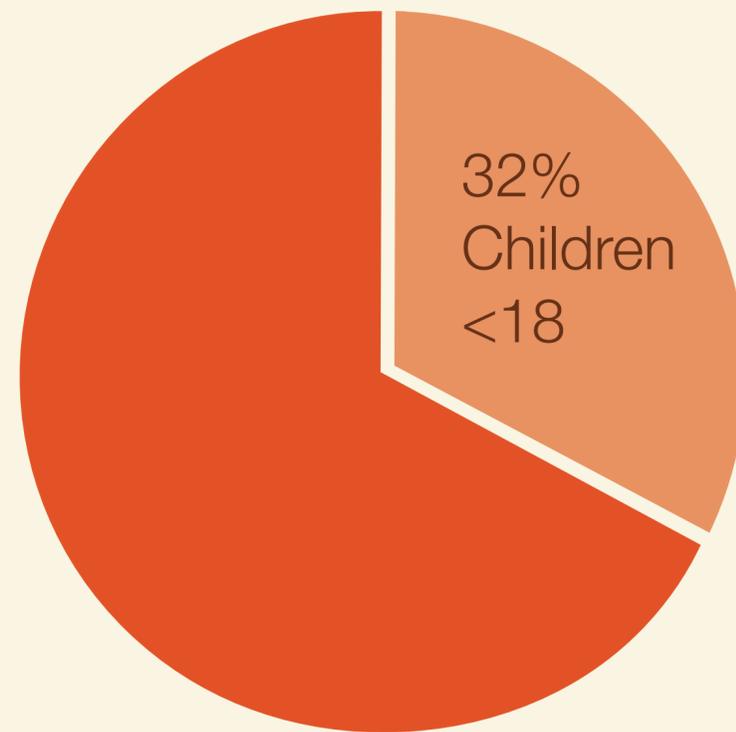
Source: Gates & Newport, Gallup, 2012.

WITHIN LGBT POPULATION

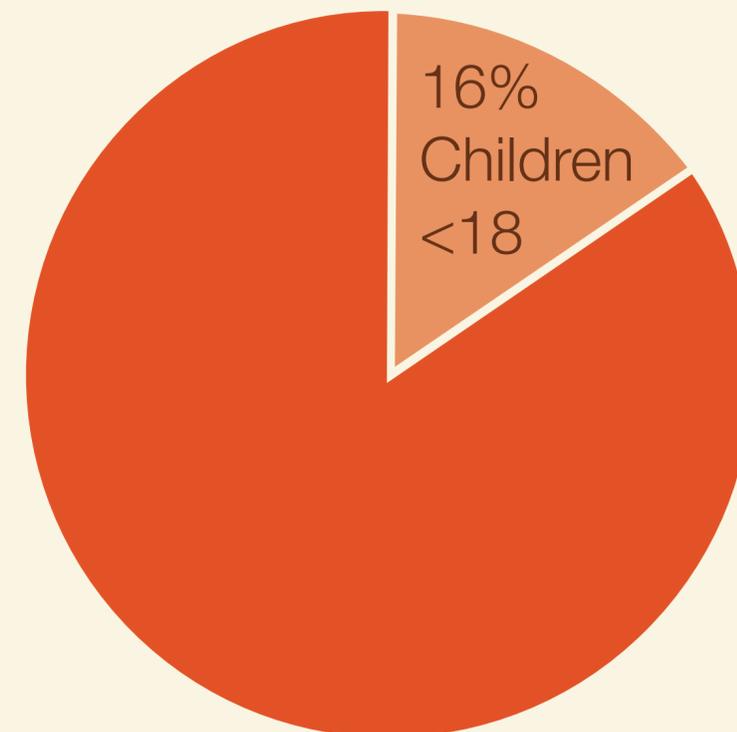


Source: Gates & Newport, Gallup, 2012.

WITHIN LGBT POPULATION



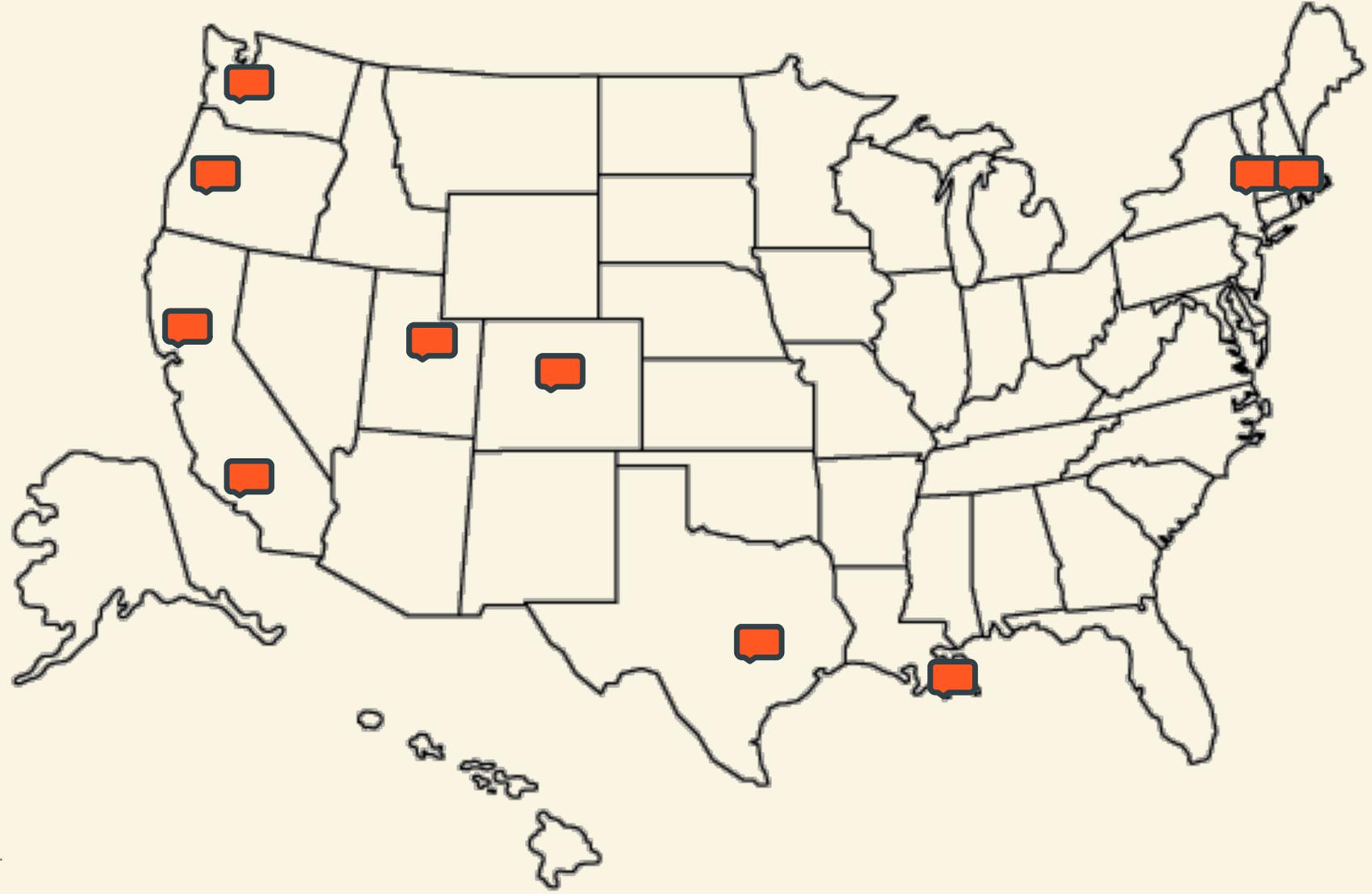
WOMEN



MEN

Source: Gates & Newport, Gallup, 2012.

METRO AREAS WITH HIGHEST PERCENTAGE



Source: Gates & Newport, Gallup, 2012.

WHAT DO WE KNOW ABOUT LGBT PEOPLE'S HEALTH

Health Disparities

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

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?**

COMMUNITY KNOWLEDGE MEETS RIGOROUS RESEARCH METHODS



CENSUS DATA & MARRIAGE 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?

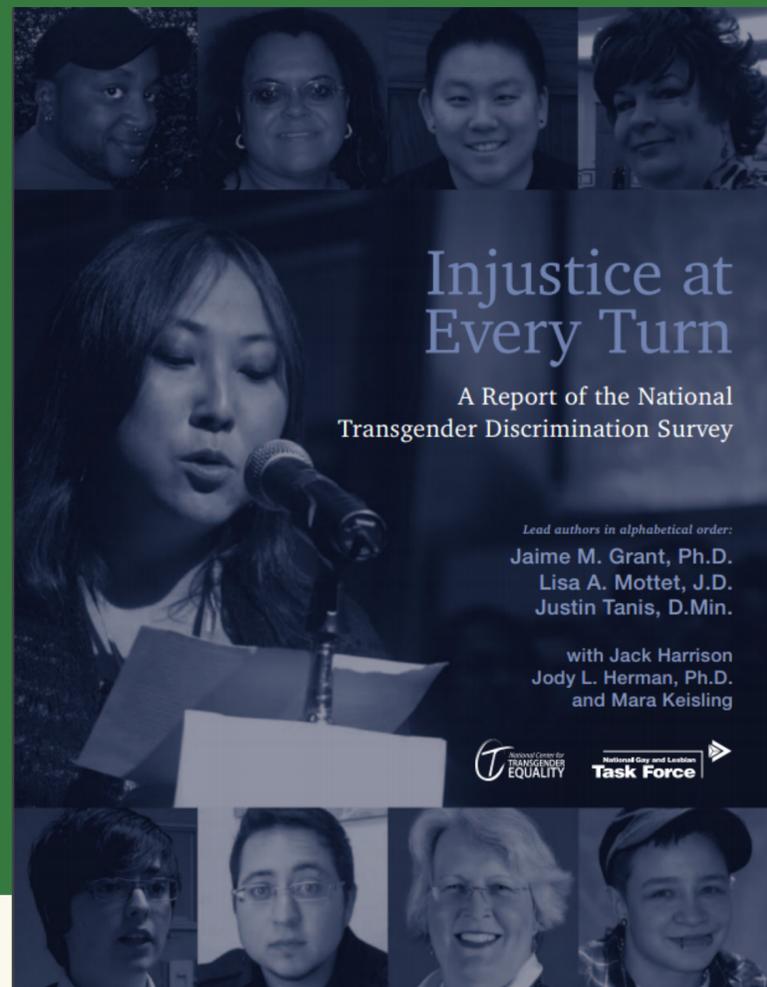
Most people coming out, raising children

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

NTDS & TRANSGENDER EQUALITY



Education Employment Health **Family Life**
Housing **Public Accommodations** Identity Documents
Police & **Incarceration**

CONTACT INFORMATION

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naomi@lgbtmap.org

MOVEMENT ADVANCEMENT PROJECT

www.lgbtmap.org

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Title

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

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

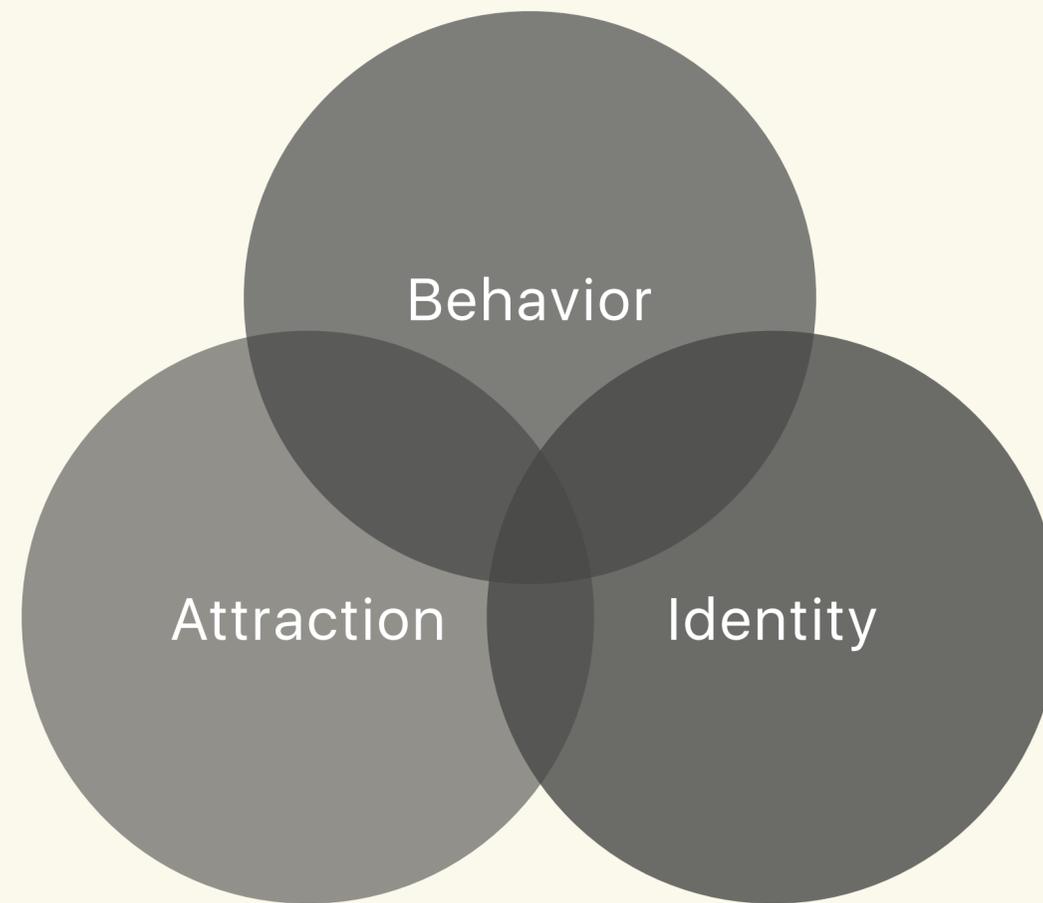
Sexual revolution: Kinsey Institute 1980

HHIV/AIDS: GSS 1988 & NHSLS 1992

Sexual & Reproductive Health: NSFG

LGBT health disparity: NHIS 2013

SEXUAL ORIENTATION AS A MULTI-DIMENSIONAL CONSTRUCT: SEXUAL BEHAVIOR, ATTRACTION & IDENTITY



DIMENSIONS OF GENDER | TRANSGENDER IDENTITY

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

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

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

LGBT ITEMS IN SURVEYS, YEAR, AGE RANGE, SAMPLE SIZE

Study	Sexual Orientation/Gender Identity Measures					Analytic Details of Measure(s)		
	Sexual Behavior	Sexual Identity	Transgender Identity	Sexual Attraction	Same-Sex Partner Household	Years Included	Valid Age Range	Analytic Sample
GSS	X	X			X	1988-2012	18+	24,003
NSDUH	X					1996	12+	18,300
NHANES	X	X				1999-2014	14-59	≈52,000
ACS					X	2000-2014	18+	27,749,435
YRBSS	X*	X*	X*	X*		2001-2009	14-18	36,774
NSFG	X	X		X		2002; 2006-13	15-44	46,669
Add Health	X	X		X	X	2005-2006	24-34	5,114
CPS					X	2010-present	18+	97,263
US CENSUS					X	2010	All Ages	308,745,538
NHIS		X			X	2013-14	18+	71,254

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

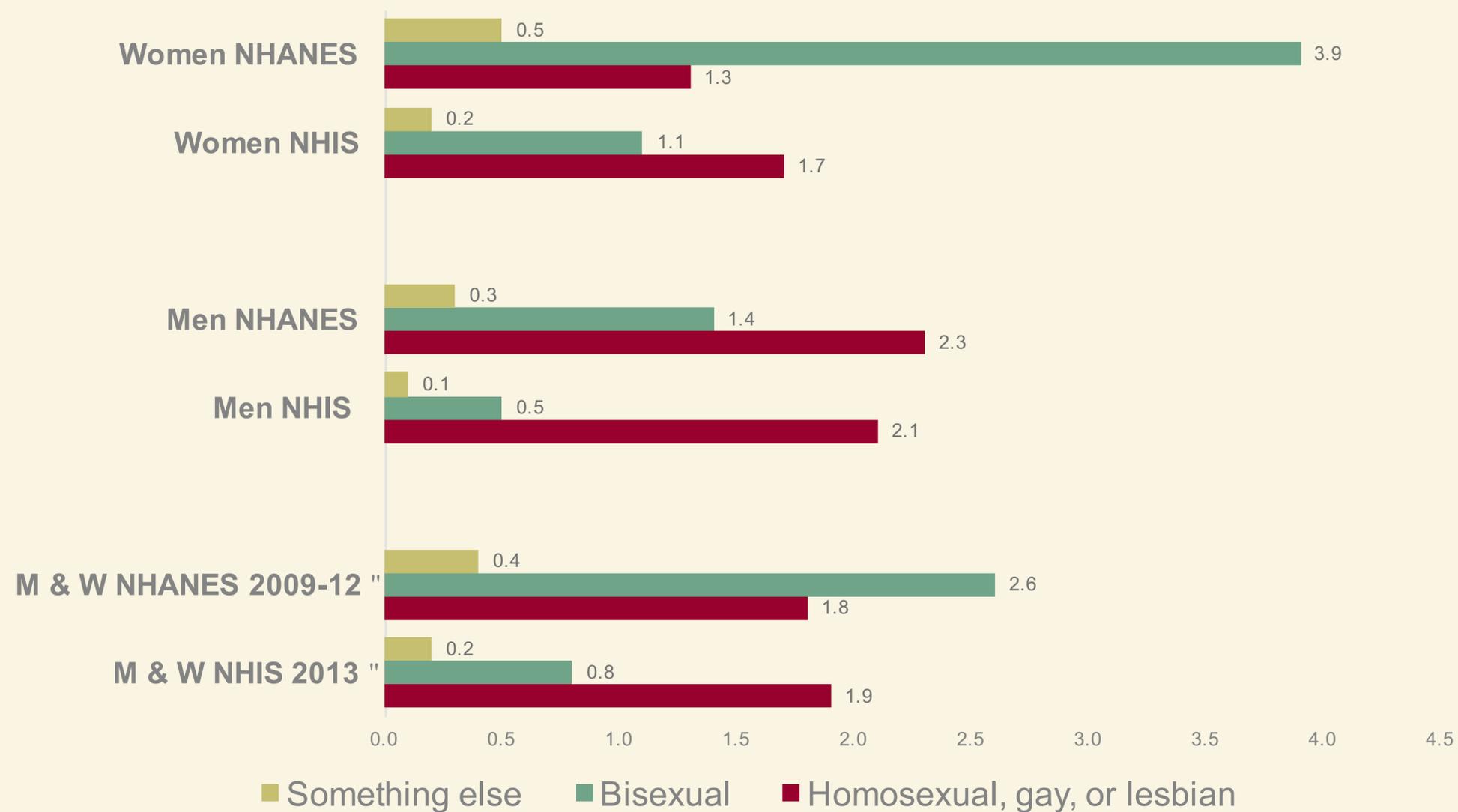
**I DON'T KNOW THE
ANSWER**

BISEXUAL

REFUSED

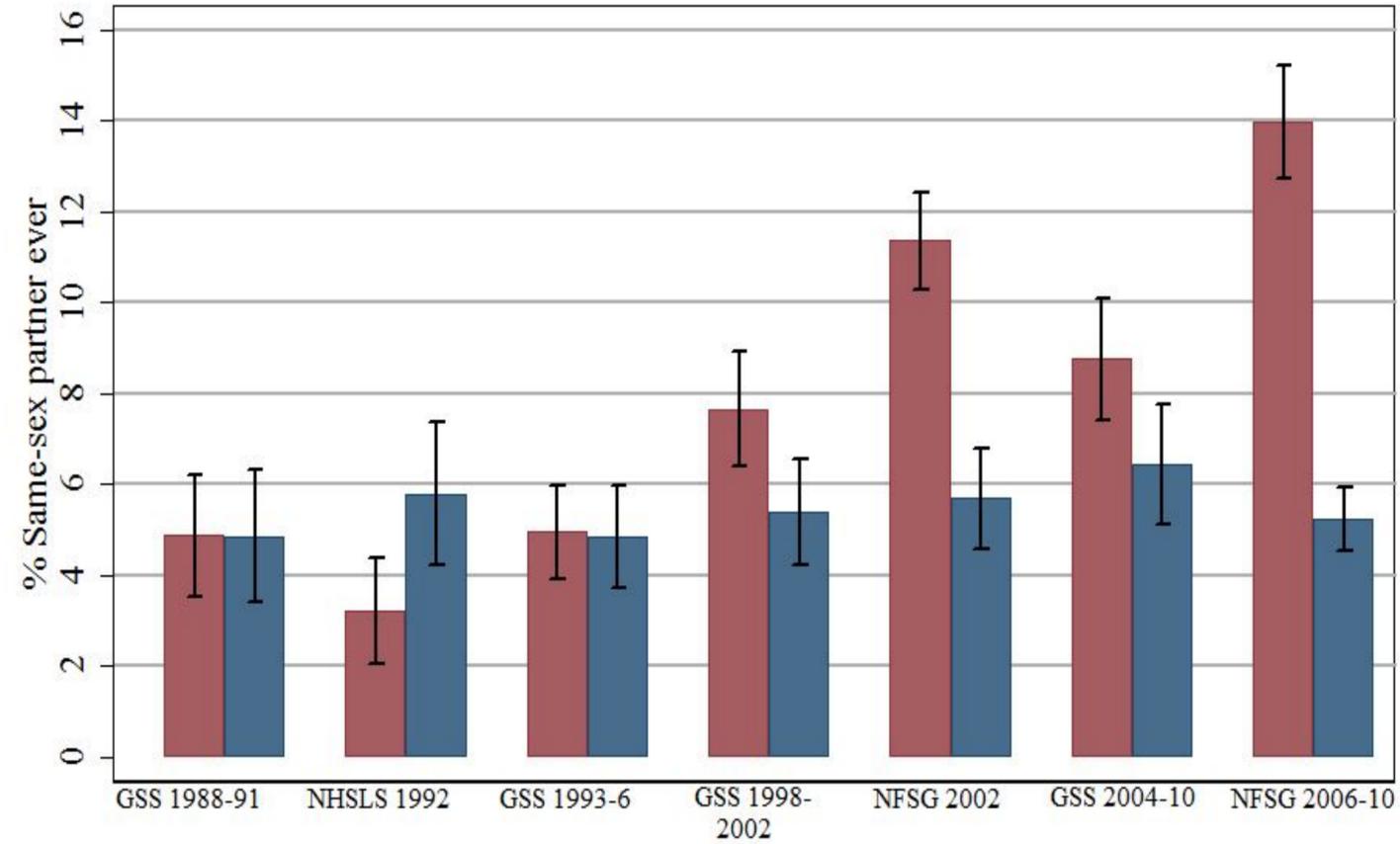
COMPARISON OF SEXUAL IDENTITY IN NHIS & NHANES

(18-59 years olds)



PERCENT SAME-SEX PARTNERS EVER FOR MEN & WOMEN

(18-44 in Selected U.S. National Survey)



Women Men
95% CI

GSSS – General Social Survey
NHLSL – National Health and Social Life Survey
NSFG – National Survey of Family Growth

SUMMARY

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

CONTACT INFORMATION

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BE CAREFUL WHAT YOU WISH FOR...

The Washington Post

National

Gay-rights groups dispute federal survey's estimate of population

By Sandhya Somashekhar August 1, 2014

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 3 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.

Data on LGBT Populations in National Surveys

GENDER IDENTITY: THE “TWO-STEP” APPROACH

ASSIGNED SEX AT BIRTH

What sex were you assigned at birth, on your original birth certificate?

- Male**
- Female**

CURRENT GENDER IDENTITY

How do you describe yourself? (check one)

- Male**
- Female**
- Transgender**
- Do not identify as female, male, or transgender**

GALLUP

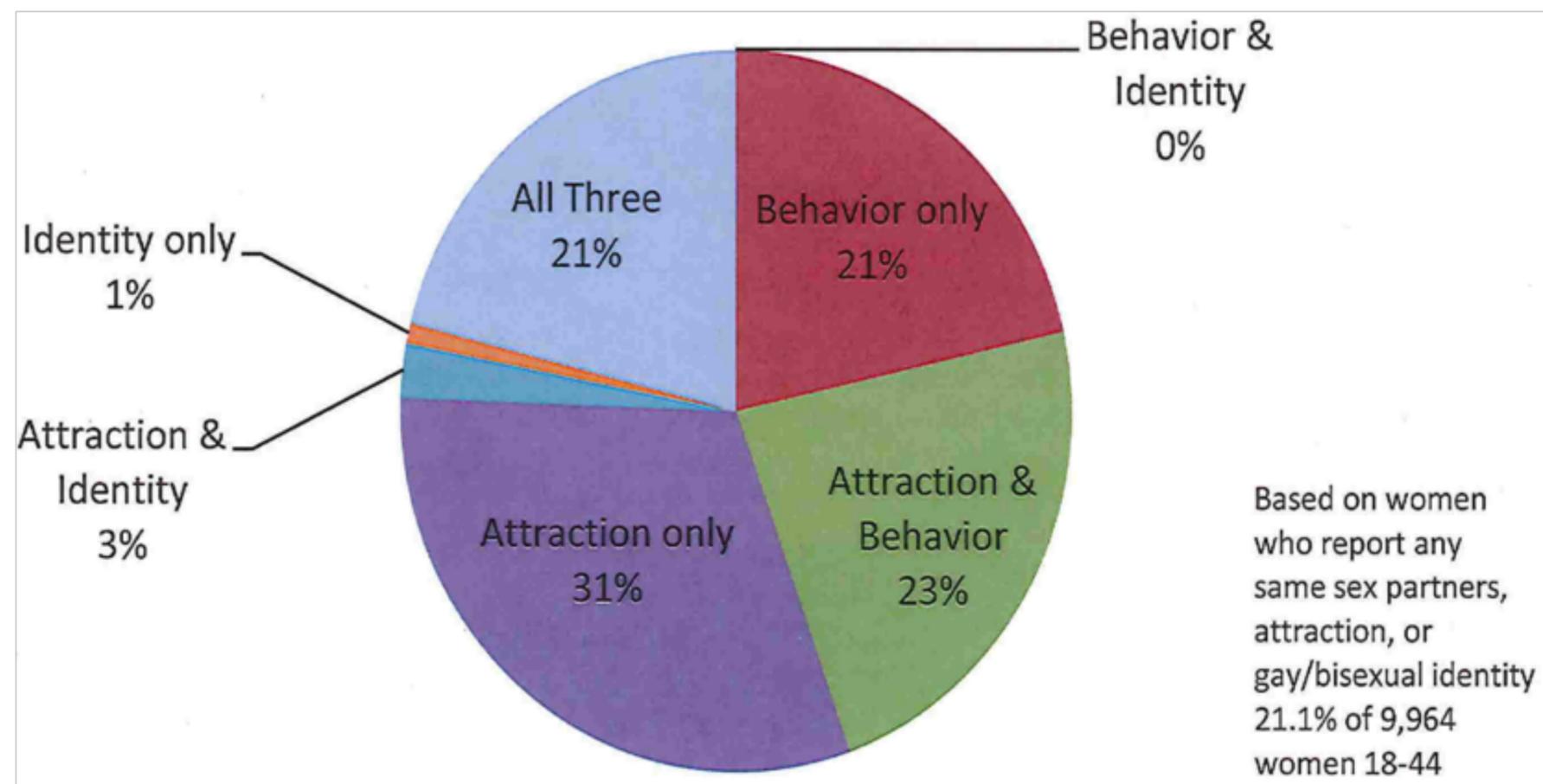
Do you, personally, identify as lesbian, gay, bisexual, or transgender?

	Yes	No	DK/Ref
	%	%	%
Men	3.3	92.5	4.2
Women	3.6	91.8	4.6

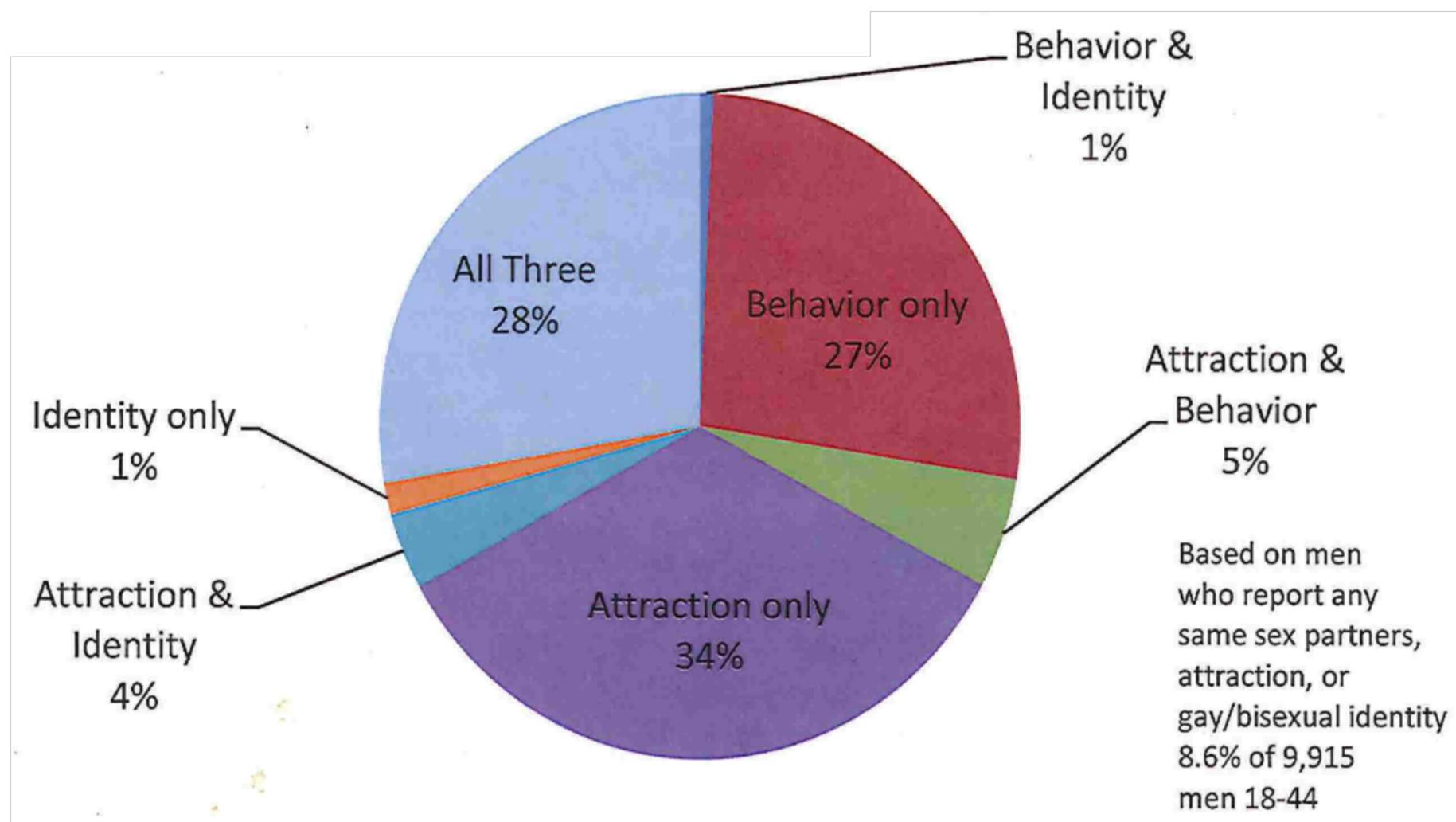
Gallup Daily tracking
June 1-Sept. 30, 2012

GALLUP®

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



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



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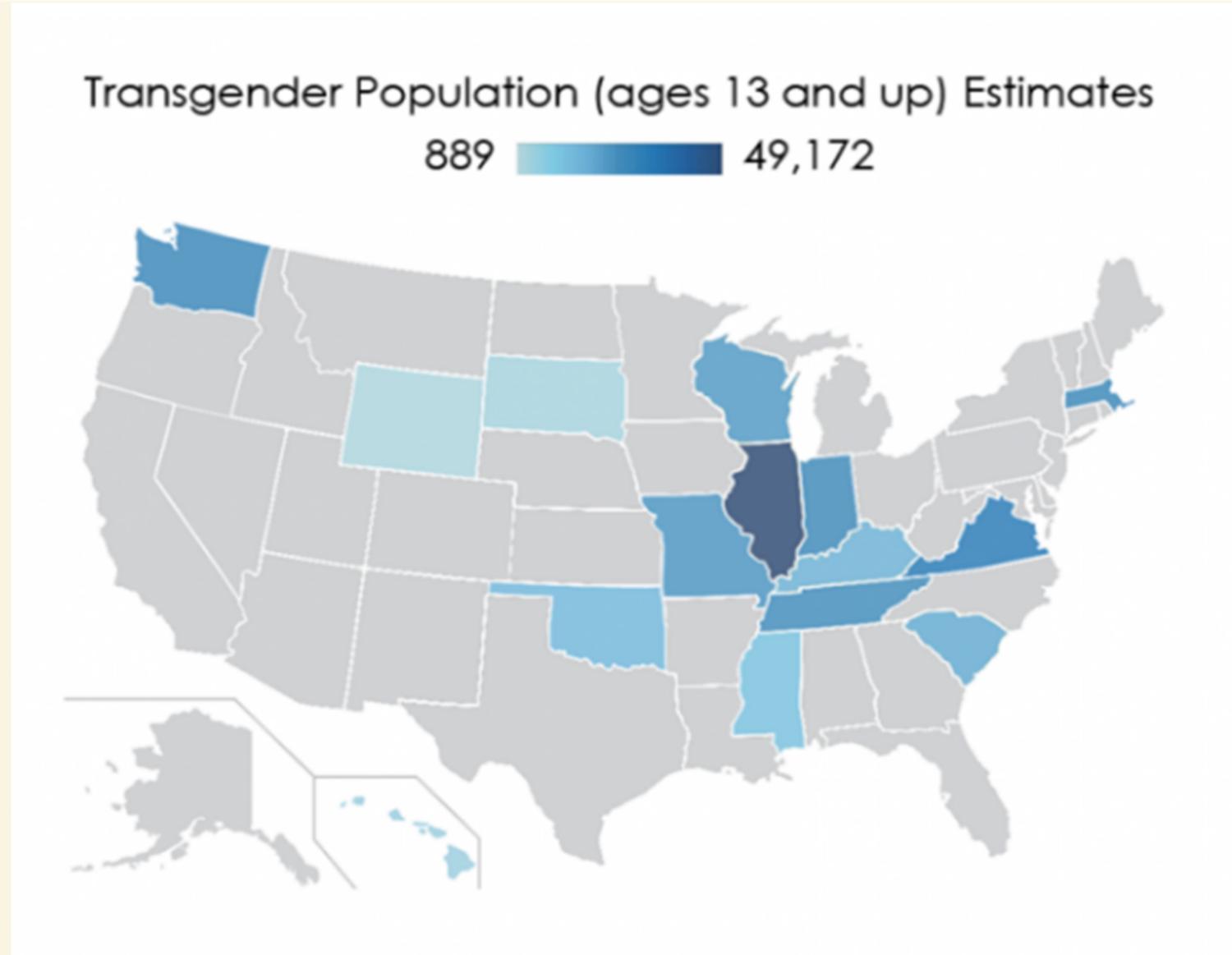
Transgender Health Research: What's Next

Jody L. Herman, Ph.D.

Scholar of Public Policy, The Williams Institute

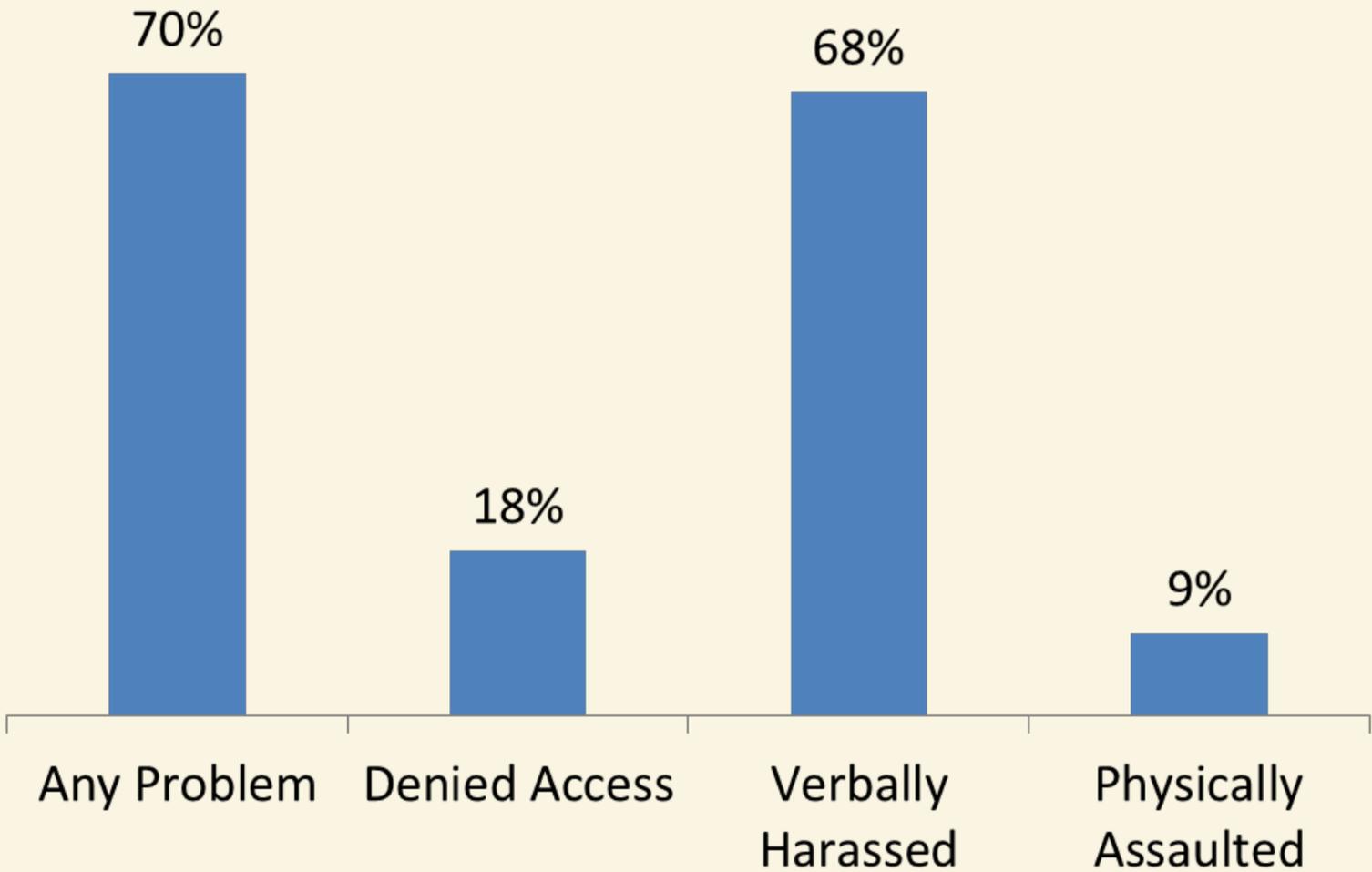
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STATES THAT INTRODUCED ANTI-TRANS LEGISLATION IN CURRENT LEGISLATIVE SESSION



BATHROOMS & SAFETY CONCERNS

**TRANS PEOPLE
ARE AT RISK**



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

2015 U.S. TRANS SURVEY

The logo features the text "U.S. Trans Survey" in white, bold, sans-serif font, centered within a blue square. The square is set against a background of thin, white, radiating lines that create a sunburst or starburst effect.

**U.S. Trans
Survey**

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

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

GENERATIONS PROJECT

generations

A Study of the Life and Health of LGB People in a Changing Society

www.generations-study.com

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).

TRANSPOP PROJECT

www.transpop.org



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 Admin-
istration** (G. Brown,
J. Shipherd, J. Blosnich,
et al)

Social Security Records

(B. Harris)

Medicare Records

(C. Haffer)

Electronic Health Records

(HHS Meaningful Use)

CONTACT INFORMATION

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WILLIAMS INSTITUTE

<http://williamsinstitute.law.ucla.edu/>

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CATALYZING EFFORTS
TO COLLECT SGM DATA



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



▶ Department of Labor

Strategic Goal: Prepare workers for better jobs



▶ Department of Labor

Strategic Goal: Ensure workplaces are safe and healthy



▶ Department of Labor

Strategic Goal: Promote fair and high quality work environments



▶ Department of Labor

Strategic Goal: Secure retirement, health, and other employee benefits and, for those not working, provide income security



▶ Department of Labor

Strategic Goal: Produce timely and accurate data on the economic conditions of workers and their families

TYPES OF BLS SURVEYS



ESTABLISHMENT

(employer based)

by Guilhem Vellut



HOUSEHOLD

(people based)

by Jason Pratt

CURRENT SURVEY POPULATION OVERVIEW

SCOPE

People aged 16+ who reside in the US

SAMPLE

60,000 Households

DATA COLLECTION

Census Bureau, in-person, proxy

REFERENCE PERIOD

Week that includes the 12th

MAIN PURPOSE

Determining labor force status

Employed

Unemployed

Not in the labor force

CURRENT, MONTHLY, ACCURATE, INFORMATIVE



Transmission of material in this release is embargoed until
8:30 a.m. (EDT) Friday, June 3, 2016

USDL-16-1096

Technical information:

Household data: (202) 691-6378 • cpsinfo@bls.gov • www.bls.gov/cps
Establishment data: (202) 691-6555 • cesinfo@bls.gov • www.bls.gov/ces

Media contact: (202) 691-5902 • PressOffice@bls.gov

THE EMPLOYMENT SITUATION — MAY 2016

The **unemployment rate** declined by 0.3 percentage point to 4.7 percent in May, and **nonfarm payroll employment** changed little (+38,000), the U.S. Bureau of Labor Statistics reported today. Employment increased in health care. Mining continued to lose jobs, and employment in information decreased due to a strike.

Chart 1. Unemployment rate, seasonally adjusted, May 2014 – May 2016

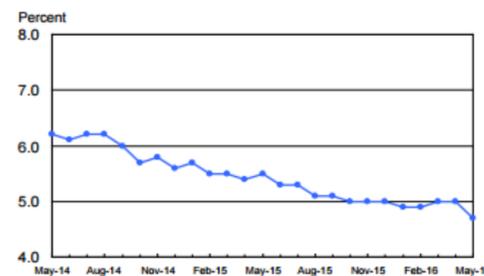
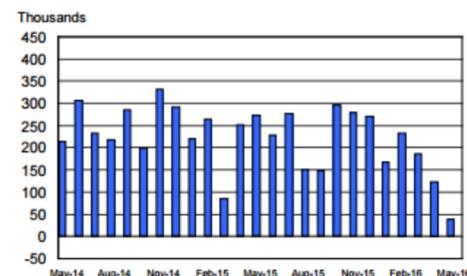


Chart 2. Nonfarm payroll employment over-the-month change, seasonally adjusted, May 2014 – May 2016

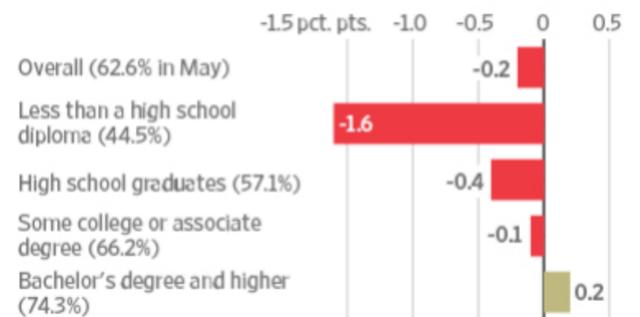


U.S. Edition | June 3, 2016 | Today's Paper

Home World U.S. Politics Economy Business Tech Markets Opinion Arts Life Real Estate

What's News

Labor-force participation, difference from the average for the first four months of 2016



SOURCE: LABOR DEPARTMENT

WSJ

U.S. Workforce Dropouts Spike as Hiring Skids

U.S. companies slowed their hiring drastically in May, to 38,000 jobs, and unemployment fell as people dropped out of the labor force, a bleak picture for the Fed before its June policy meeting on interest rates. 495

Venezuelans, Facing Food Shortages, Rally Behind Vilified Conglomerate

Empresas Polar and its chief executive, Lorenzo Mendoza, have been blamed by Socialist leaders for widespread food shortages, but the company remains wildly popular with ordinary citizens. 181



J.P. Morgan: You Don't Always Have to Wear a Suit

In a break from tradition, J.P. Morgan is loosening its dress code to allow employees to wear business-casual attire on most occasions, a relatively unusual move for a Wall Street bank. 50



- Quiz: Can You Wear This at J.P. Morgan?
- J.P. Morgan Makes Move to Business Casual



Election 2016: Full Coverage



Besieged Syrian Town Goes Wanting Another Day

DEMOGRAPHIC DATA



RELATIONSHIP TO REFERENCE PERSON

MAY 2015

Interviewers
provided flash
cards

Asked
during 1st
month's meeting

No data
available (yet)

Large error
measures

Current Population Survey - Ver 15.43.05

Forms Answer Navigate Options Help Hide Watch Window

CPS ADDR FAQ Chg Resp ROS OPTOUT Exit/F10

How is Jane Doe related to you?

42. Opposite-sex Spouse (Husband/Wife)

43. Opposite-sex Unmarried Partner

44. Same-sex Spouse (Husband/Wife)

45. Same-sex Unmarried Partner

46. Child

47. Grandchild

48. Parent (Mother/Father)

49. Brother/Sister

50. Other relative (Aunt, Cousin, Nephew, Mother-in-law, etc.)

51. Foster child

52. Housemate/Roommate

53. Roomer/Boarder

54. Other nonrelative

	Name	Mem	Sex	Relationship
[1]	Judy Doe	1	2	
[2]	Jane Doe	1	2	45
[3]	John Anderson	1	1	53
[4]	Johnny Anderson	1	1	53
[5]				
[6]				
[7]				
[8]				
[9]				
[10]				

DEP Watch Window - 00000111

00000111 S_RRP 11:24:40 AM 3/17/2015 2 Judy Doe 50/523

HOW DO QUESTIONS GET ADDED?

Identified potential need

Cogitative tested

Do respondents understand what we are asking?

Federal Register Notice/OMB approval

Literature search/subject matter expert

Respondent burden

Fully specified

Are we asking what we think we are asking?

Response rate

TESTING SEXUAL ORIENTATION QUESTIONS

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

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

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>

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QUESTIONS AND ANSWERS

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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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