



Measuring Sex, Gender Identity, and Sexual Orientation

A Consensus Study Report by the National Academies
Commissioned by the National Institutes of Health

Karen L. Parker, PhD, MSW

(Pronouns: She, Her)

Director

Sexual & Gender Minority Research Office

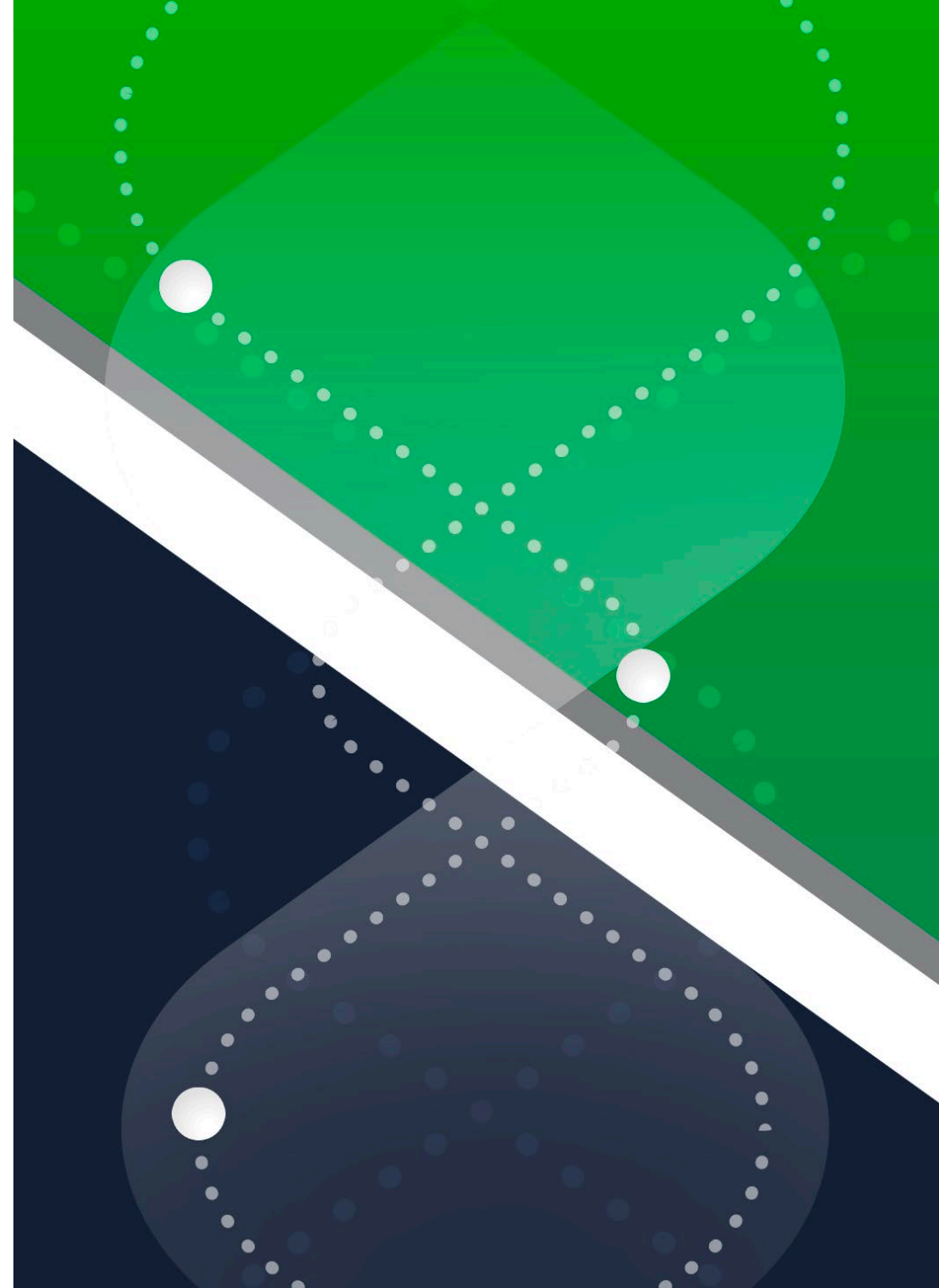
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BACKGROUND






SGMRO – What We Do

- **Coordinate** sexual and gender minority (SGM) health research activities across NIH
- **Represent** NIH at conferences and events focused on SGM research
- **Serve** as a resource for the extramural and NIH communities about SGM-related research activities
- **Connect** extramural researchers with key NIH contacts
- **Convene** conferences and workshops to inform priority-setting and research activities
- **Collaborate** with NIH Institutes and Centers on the development of SGM health research reports
- **Lead** implementation of the NIH SGM Strategic Plan
- **Leverage** resources and develop initiatives to support SGM health research

Current Measurement Challenges

- No official standards
 - Labels/definitions are fluid and rapidly changing
 - Many terms are unfamiliar to sexual majorities and cisgender populations
 - Official statistics require time-series, repeated measures over time
 - Lack of production survey vehicles to conduct experiments
 - Need for translations into languages other than English
 - Questions must work for interviewer and self-administered response modes, as well as when asking proxies to respond for other household members
 - Dearth of research on measuring intersex or DSD
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Report Sponsor

- NIH commissioned the National Academies of Sciences, Engineering, and Mathematics (NASEM) to convene a panel of experts to review the existing knowledge base related to SGM-related measurement, make recommendations for specific measures, and provide guidance for their use
- **This effort was led by SGMRO, and was co-funded by 18 other NIH components**

Report Co-funders

- Sexual & Gender Minority Research Office
- *All of Us* Research Program
- *Eunice Kennedy Shriver* National Institute of Child Health & Human Development
- National Cancer Institute
- National Human Genome Research Institute
- National Institute on Aging
- National Institute of Allergy & Infectious Diseases
- National Institute of Environmental Health Sciences
- National Institute of Mental Health
- National Institute of Minority Health & Health Disparities
- National Institute of Neurological Disorders & Stroke
- Office of AIDS Research
- Office of Behavioral and Social Sciences Research
- Office of Disease Prevention
- Office of Equity, Diversity Inclusion
- Office of Intramural Training & Education
- Office of Research on Women's Health
- Office of Strategic Coordination
- Scientific Workforce Diversity

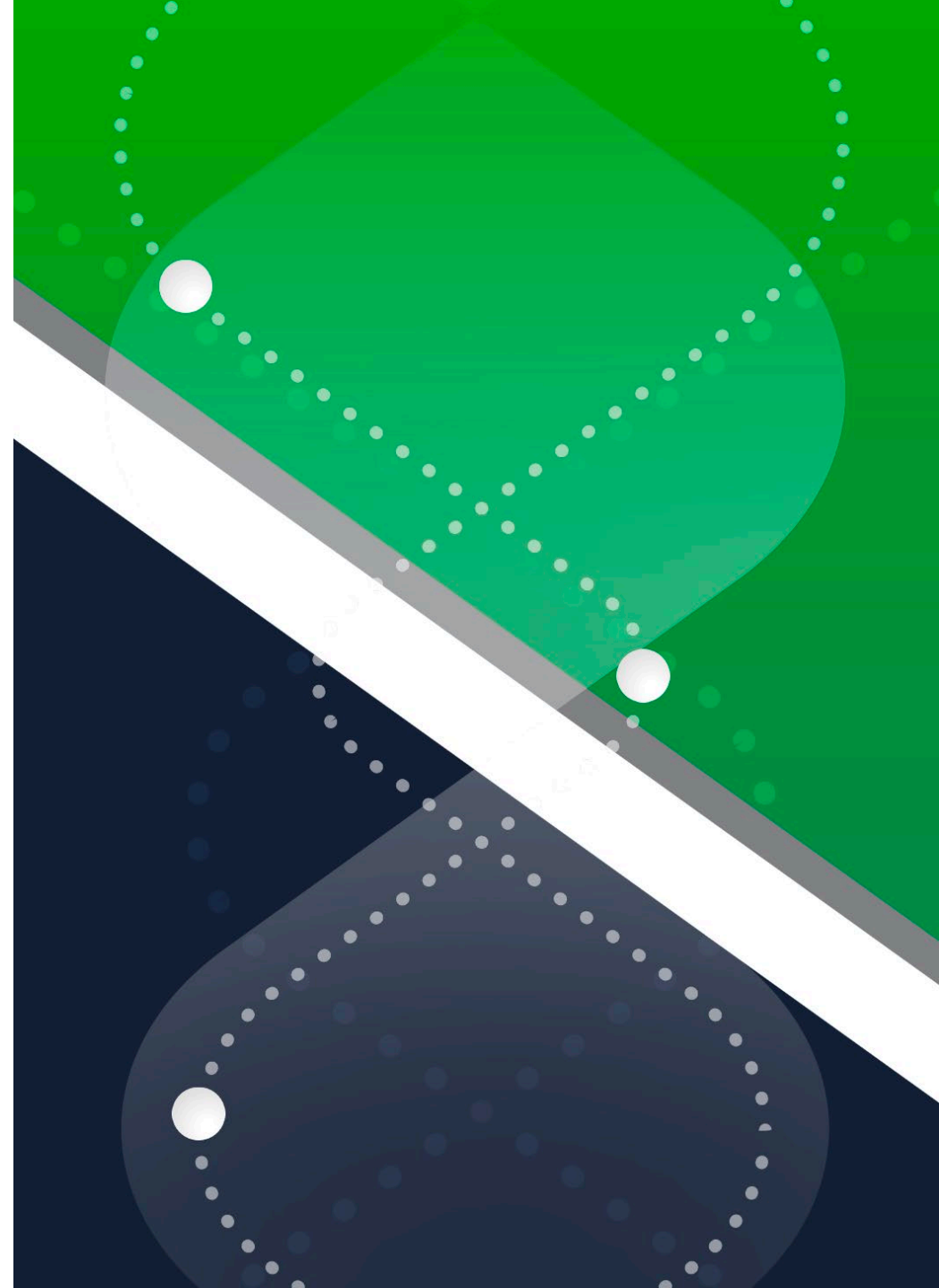
Statement of Task

1. Review current measures and the methodological issues related to measuring sex as a nonbinary construct, gender identity, and sexual orientation in surveys and research studies, in administrative settings, and in clinical settings.
 2. Produce a consensus report with conclusions and recommendations on guiding principles for collecting data on sex, gender identity, and sexual orientation and recommended measures for these constructs in different settings.
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Scope of Report

- Measures that can be used in the U.S. English-speaking adult population
 - More detailed response options may be necessary for measures used within LGBTQI+ populations
 - Modifications to recommendations may be needed if they are used within younger populations
 - Prioritizes representation of indigenous sexual and gender minorities
- Focus solely on measures of identity for counting and identifying members of sexual minority populations
 - Identity dimension is most relevant for measuring disparities in treatment and outcomes
 - Greater effort has been spent on developing and deploying measures of identity than for other dimensions

REPORT RECOMMENDATIONS





Guiding Principles

- **Inclusiveness**
 - People deserve to count and be counted
- **Precision**
 - Use precise terminology that reflects the constructs of interest
- **Autonomy**
 - Respect individual identity and autonomy
- **Parsimony**
 - Collect only necessary data
- **Privacy**
 - Use data in a manner that benefits respondents and respects their privacy and confidentiality

Key Takeaways & Considerations

- The standard for the National Institutes of Health should be to collect data on gender and report it by default.
- Collection of data on sex as a biological variable should be limited to circumstances where information about sex traits is relevant.
 - Collection of data on sex as a biological variable should be accompanied by collection of data on gender.
 - Data collection efforts should not conflate sex as a biological variable with gender or otherwise treat the respective concepts as interchangeable.
- Response options of “I don’t know” and “Prefer not to answer” should only be used where it is required to respond.
- Reporting of the use of write-in categories in published tabulations of responses is strongly encouraged.
 - Continued testing and use of write-in response options is needed.

Sex as a Biological Variable Policy

- More often than not, basic and preclinical biomedical research has focused on male animals and cells. An over-reliance on male animals and cells may obscure understanding of key sex influences on health processes and outcomes.
 - Accounting for sex as a biological variable begins with the development of research questions and study design.
 - SABV also includes data collection and analysis of results, as well as reporting of findings.
- SABV can work in collaboration with gender identity and nonbinary sex data:
 - In human studies, collecting gender identity data does not subvert or replace the need and requirements for SABV to continue in basic research.
 - SGMRO is working with ORWH to develop specific information related to ensuring that SABV works collaboratively with sexual and gender minority research and data.



Two-Spirit Response Category

- A Two-Spirit response category for AI/AN respondents in both the sexual orientation and gender identity groups should be included in situations when Indigenous populations can identify themselves.
- Because Two-Spirit is a term by and for Indigenous peoples and is culturally anchored with meaning and, potentially, social status, it is not appropriate for use by non-Indigenous populations.

Recommended Measure

Which of the following best represents how you think of yourself? [Select ONE]:

- ☐ Lesbian or gay
 - ☐ Straight, that is, not gay or lesbian
 - ☐ Bisexual
 - ☐ [If respondent is AIAN:] Two-Spirit
 - ☐ I use a different term [free text]
- (Don't know)
- (Prefer not to answer)

Recommended Topics for Future Research

- Alternate wording for the “straight” response option
- Ordering of response categories
- Guidelines for measures that capture other dimensions of sexual orientation (i.e., attraction, behavior)
- Addition of sexual orientation response options that may be more prevalent in subsets of the LGBTQI+ population (e.g., queer, questioning)
- Evaluation of existing measures and identification of best practices for collecting data among sexual minority adolescents
- Impact of proxy reporting of sexual orientation identity

Recommended Measures

Q1: What sex were you assigned at birth, on your original birth certificate?

☐ Female

☐ Male

(Don't know)

(Prefer not to answer)

Q2: What is your current gender identity [Select ONE]

☐ Female

☐ Male

☐ Transgender

☐ [If respondent is AIAN:] Two-Spirit

☐ I use a different term: [free text]

(Don't know)

(Prefer not to answer)

Recommended Topics for Future Research

- Testing of current gender-specific response categories and optimal response ordering
- Alternative two-step gender measures that offer an inclusive count of gender minorities without asking sex assigned at birth
- Assessment of inclusion of “nonbinary” in gender identity response categories
- Utility of including a nonbinary response when asking about sex assigned at birth and how to count responses in terms of gender
- Expanding testing of the two-step measure beyond general population assessments of English-speaking adults
- Evaluation of a “select all that apply” option for the current gender question

Recommended Measure

Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?

☐ Yes

☐ No

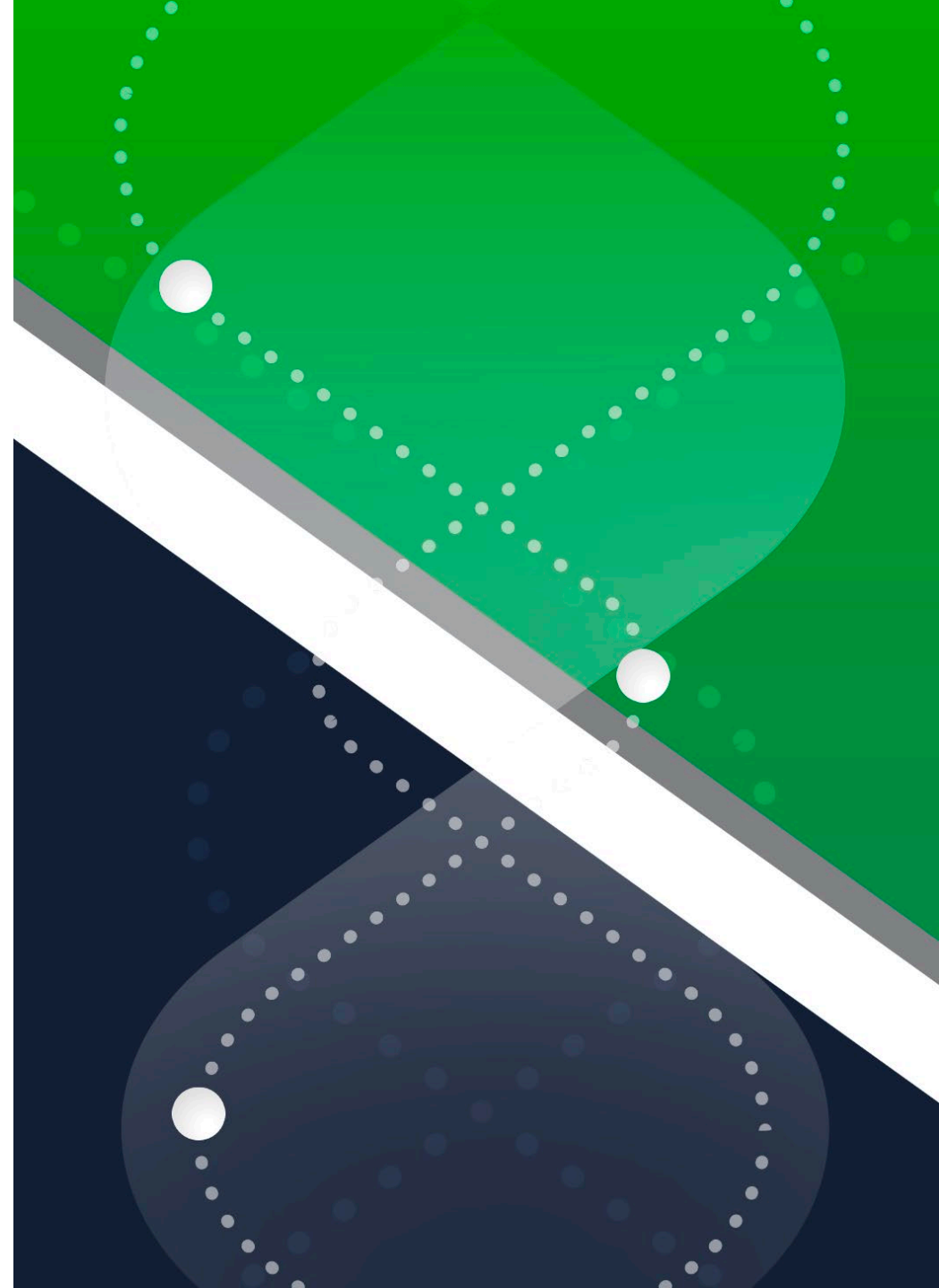
(Don't know)

(Prefer not to answer)


Recommended Topics for Future Research

- Additional testing of single-item intersex/DSD status questions
- Efficacy of the three intersex/DSD measures highlighted within the report to determine which measure most effectively identifies the intersex/DSD population in a range of settings
- Effects of including definitions and examples of terms used in intersex status questions, such as “intersex,” “DSD,” and specific intersex variations
- Effects of proxy reporting of intersex/DSD status, particularly of caregivers reporting their children’s status

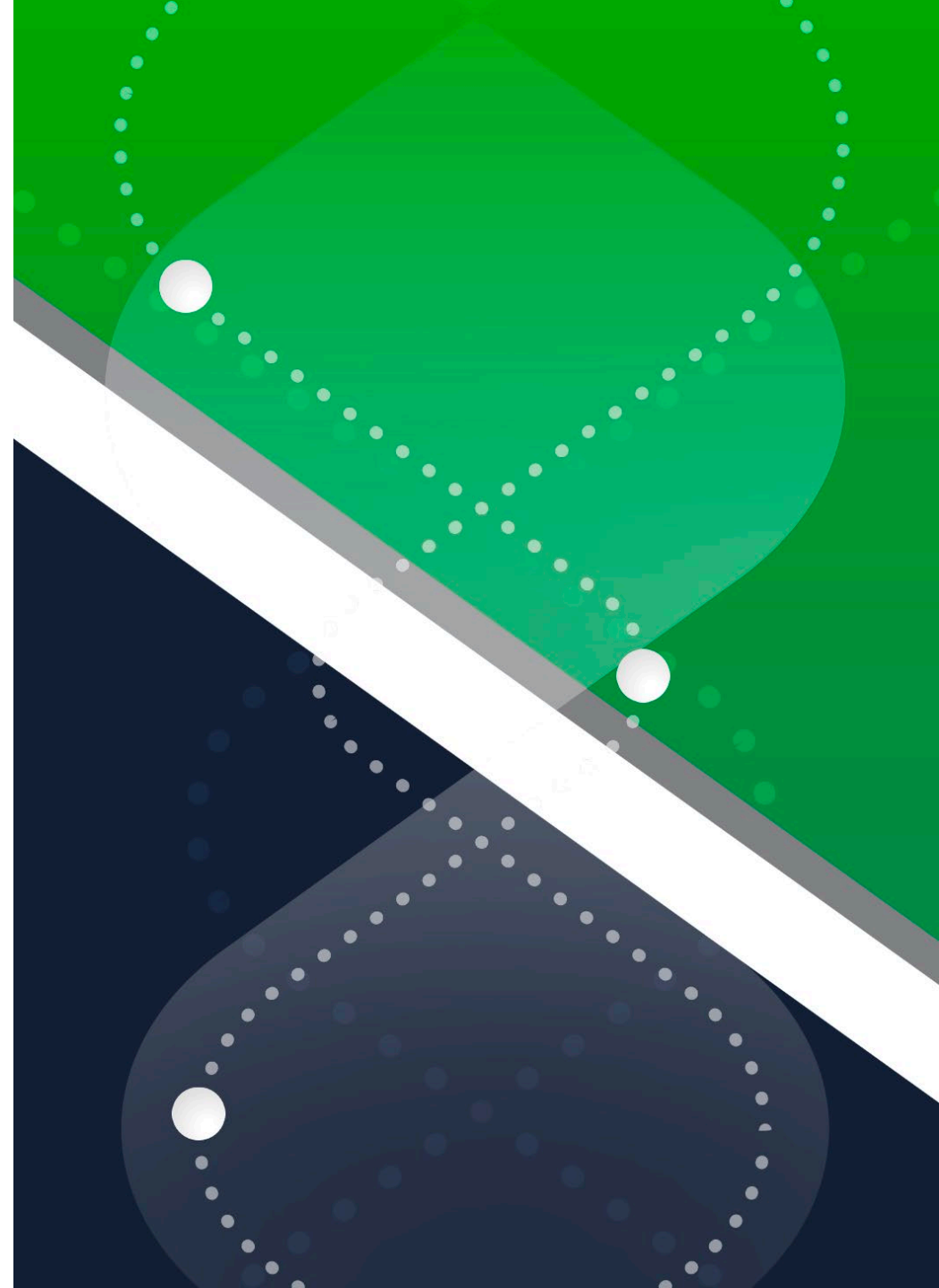
LOOKING AHEAD



Future Directions for SGMRO

- Collaborate with the SGM RCC to map opportunities at ICOs to add and/or update recommended questions as data systems and surveys are aligned
 - Update and refresh the SGMRO website and related measurement webpages to feature and highlight the recommendations from the NASEM report
 - Collaborate and provide technical assistance across NIH, HHS, and interagency work groups to add the NASEM recommendations where appropriate or develop testing of new measures outlined in the future research recommendations
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- **Aliya Saperstein**, Stanford University
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External Reviewers & NASEM Staff

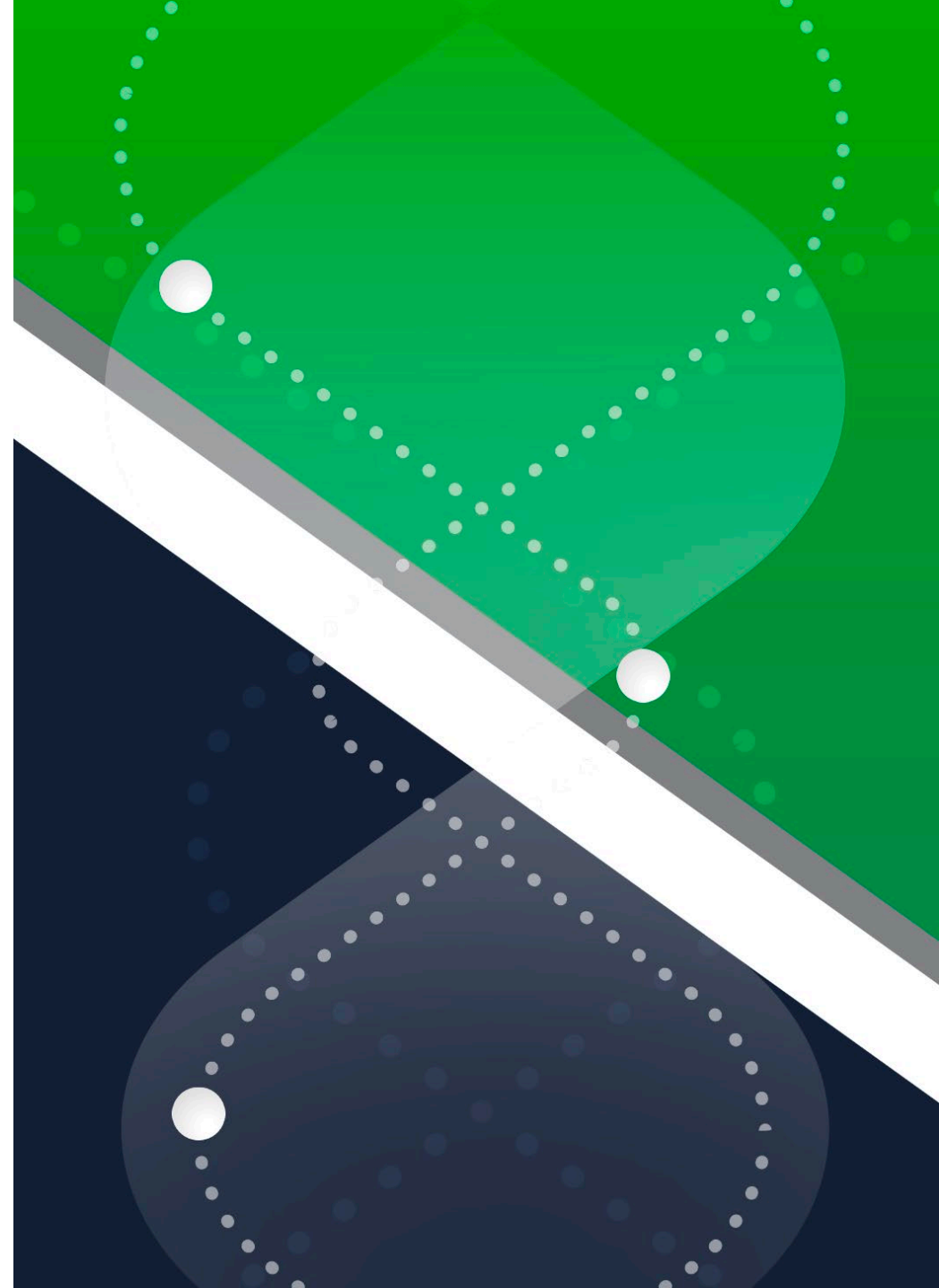
EXTERNAL REVIEWERS

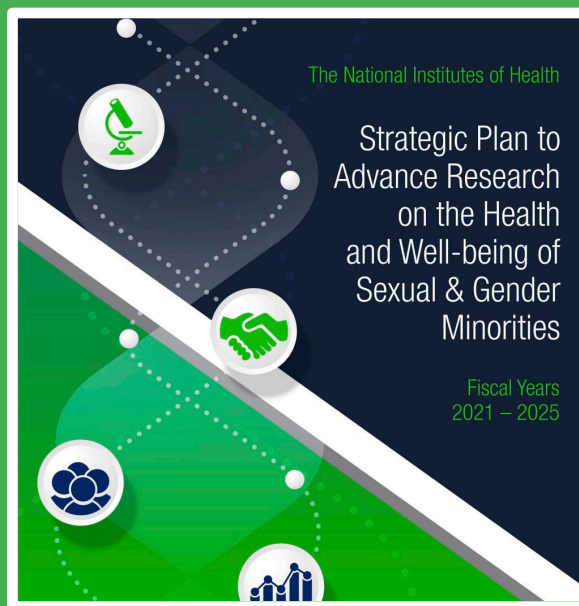
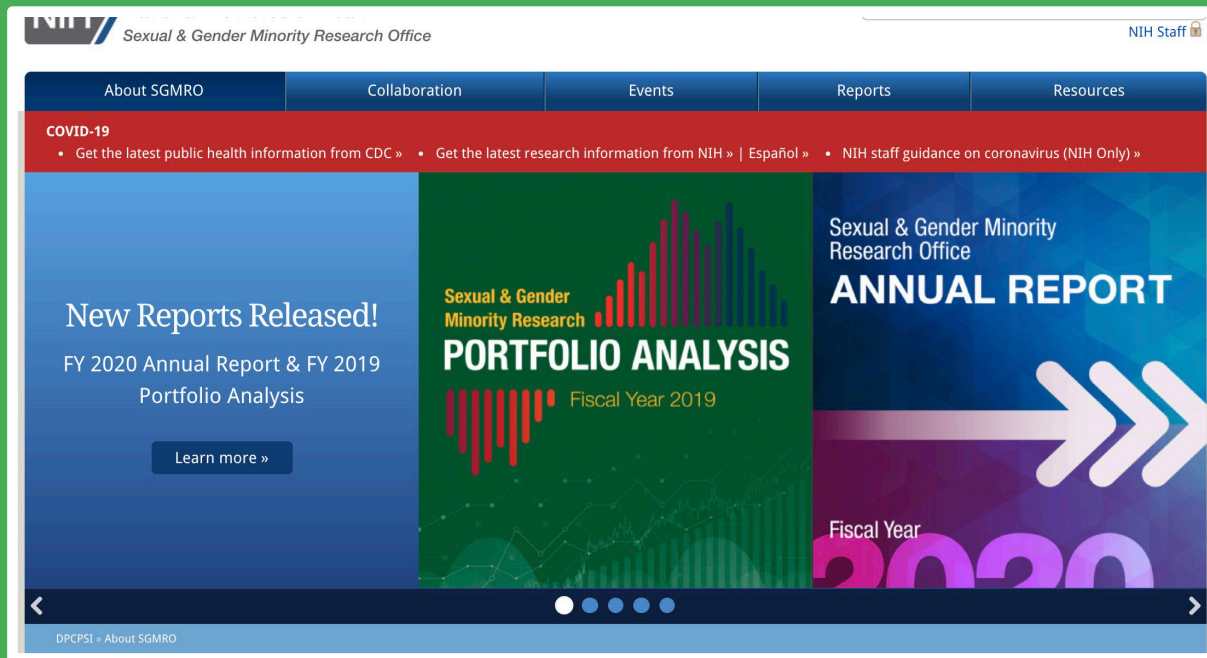
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- **Kari J. Dockendorff**, Colorado State University
- **Margo Edmunds**, Academyhealth
- **Jason D. Flatt**, University of Nevada, Las Vegas
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- **Carl Streed**, Boston University School of Medicine

NASEM STAFF

- **Tara Becker**, Study Director
- **Katrina Stone**, Senior Program Officer

THANK YOU!





Connect with Us



Office E-mail:
SGMRO@nih.gov

Karen Parker, PhD, MSW
karen.parker@nih.gov

Irene Avila, PhD
irene.avila@nih.gov

Website: <https://dpcpsi.nih.gov/sgmro>

Sign-up for NIH SGM Listserv:
<https://tinyurl.com/NIHSGMLIST>