Urology Interagency Coordinating Committee (UICC)
Bathroom Access and Bladder Health
Friday, December 8, 2017
9:00 a.m. - 12:00 p.m.
6707 Democracy Blvd. Room 7050, Bethesda, MD
Meeting Minutes

NIDDK Participants:
Tamara Bavendam
Ziya Kirkali
Jenna Norton
Kevin Abbott
Andy Narva
Emily Duggan
Rob Star
January Payne
Sandeep Dayal
Yining Xie
Chris Mullins
Eleanor Hoff

Other Participants:
Brooke Leggin, OWH
Doug Trout, NIOSH
Candice Johnson, NIOSH
Carissa Rocheleau, NIOSH
Lisa Halverson, NICHD
Timothy Cunningham, CDC
Karen Parker, Sex and Gender Minority Research Office, OD
Alayne Markland, U Alabama Birmingham
Cecelia Hardacker,
Mary Worstell, OWH
Andrew Hruszkewycz, NCI

Welcome

Dr. Star opened the meeting and welcomed participants. Meeting participants introduced themselves and noted their affiliations.

Setting the Stage
Tamara Bavendam, NIDDK

Dr. Bavendam discussed the Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. The PLUS Network uses the social ecological model to guide broad inclusion of all variables that might be related to lower urinary tract conditions in women and girls: societal, community, institutions/organizations, interpersonal, and individual. Dr. Bavendam noted that this conceptual framework was adapted from Glass and McAtee, and includes other levels of influence within one's social ecology, including institutions such as work and school, relationships with close others such as family and friends, and our individual thoughts, feelings and behaviors. Bathroom access has emerged in PLUS as an important factor in bladder health, and today's meeting will consider this topic from two different angles – gender identity and occupation.

Part I: Bladder Health and Bathroom Access for the Transgender Population

Sexual and gender minority activities at NIH
Karen L. Parker, Ph.D., M.S.W., NIH Sexual & Gender Minority Research Office

Dr. Parker began her presentation with the Sex and Gender Minority Research Office (SGMRO) definition of sexual and gender minority which is as an umbrella phrase that encompasses lesbian, gay, bisexual, and transgender populations as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms." The language serves to be inclusive; however, this area of research is vastly evolving. Based on 2011 data, Dr. Parker reported the following population estimates:

- Lesbian/Gay women: 1.1%
- Bisexual women: 2.2%
- Gay men: 2.2%
- Bisexual men: 1.4%
- Transgender: 0.6%

SGM populations have higher rates of suicide, HIV/AIDS, self-harming behaviors without lethal intent, harassment from grades K-12, long-term concerns about hormone use, and discrimination from medical professionals. These rates disproportionately affect Latinos and African Americans compared to other ethnic groups. The transgender population has higher rates of homeless youth, hostility and discrimination from medical professionals, substance abuse, depression, and anxiety.

In addition to the NIH Sexual & Gender Minority Research Office, Dr. Collins established a long-standing NIH coordinating committee for SGM activities. Drs. Dayal and Bavendam represent NIDDK at this committee.

Dr. Parker reviewed the new SGM strategic plan goals:

1. Expand the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research
2. Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research about SGM Health and Well-being
3. Strengthen the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Well-being
4. Evaluate Progress on Advancing SGM Research

Dr. Parker noted the following highlights from the FY16 Portfolio Analysis Findings

- Among NIH Institutes (in order of largest to smallest), NIMH, NIDA, NIAID, NIAA, NIMHD, and NCI funded the highest numbers of SGM-related projects
- Among NIH projects (in order of largest to smallest), NIAID, NIDA, NIHMH, NICHD, and NCI contributed the highest levels of funding for SGM-related projects.

- For the number of SGM-related projects by state, Dr. Parker noted that most projects were located in CA, WA, NY, PA, NC, TX, FL, GA, MI, OH, IL, MN, and Washington, DC

The number of SGM-related projects increased by 9% from FY2015 to FY2016, and by 44% since 2010 (232 vs. 334). For FY2018, the SGMRO has planned a measurement workshop, a "Points to Consider in SGM Research" document, a regional SGM Research Workshop in Boston on May 12 (different agencies invited), investigator awards in SGM health research, and a review of NIH SGM Research Strategic Plan.

Discussion

Dr. Abbott noted that there is an active funding opportunity from NIDDK: "Urological Epidemiology (UroEpi) Institutional Research Career Development Program (K12)" at https://grants.nih.gov/grants/guide/rfa-files/RFA-DK-15-007.html. Dr. Abbott requested a list of meetings/workshops from Dr. Parker.

Working with sex and gender minority populations in urologic research
Cecilia T. Hardacker, MSN, RN, CNL, Howard Brown Health & Rush University College of Nursing

Ms. Hardacker presented findings on working with SGM populations in urologic research. Ms. Hardacker serves as a Consultant for the NIH PLUS Consortium through Loyola University. Ms. Hardacker discussed the PLUS RFA and how the Consortium had to refine and clarify some of the terminology. For example, the group clarified that the term "lower urinary tract" was intended to be inclusive of bladder, pelvic floor musculature, urethra". The terminology was revised to establish inclusion/ exclusion criteria early.

Even the term female required significant discussion. Was the RFA referring to sex or gender? The consortium had to become familiar with the following terminology:

Gender Identity Term	Definition
Female	**A person whose self-identifies as female**
Male	**A person whose self-identifies as male**

Cisgender	**1. A person whose gender identity is congruent to their sex assigned at birth** **2. Academic comparative term with TGNC people**
Transgender	**A person whose gender identity is different from the sex they were assigned at birth (Merriam-Webster Online Dictionary, 2015)**
Gender Non-Conforming	**A person who does not identify with the male-female binary, rather, seeks another gender option authentic for themselves (Gender Equity Resource Center, 2014)**
Gender Queer	**An identity that actively seeks a unique safe place**

Sexual Orientation Term	Definition
Lesbian	**A female identified person who is emotionally, intellectually, romantically, spiritually attracted to another female-identified person**
Gay	**A male identified person who is emotionally, intellectually, romantically, spiritually attracted to another male-identified person**
Bisexual	**A person who has the potential for a relationship with either male/female people**
Pansexual	**A person who has the potential for a relationship with all genders**
Asexual	**A person who is not interested in sexual acts of intimacy rather other means of connecting with another person**

Sexual Orientation	Sexual Behaviors	Sex assigned at birth	Gender Identity
Lesbian eg. Dyke, Femme, Butch	**WSW**	**People born with cervix, ovaries, uterus,**	**Female**

		(XX), short urethras	
Bisexual	**WSWSM**		**Gender queer**
Queer			**Gender Non-Conforming**
			Transman

Ms. Hardacker displayed several measurement examples reviewed by PLUS Consortium investigators to help PLUS make decisions. Ms. Hardacker emphasized the importance of standardizing measurement protocols across all federal agencies, and cited data from other studies, such as the "Prevalence of overactive bladder and stress incontinence in women who have sex with women: an internet-based survey." Study findings indicated that stress UI and OAB may be prevalent in women who have sex with other women (WSW), suggesting that further attention to urological health is needed in this population. Research also suggests poorer health-related quality of life in WSW compared to straight women.

The use of terminology from a feminist perspective, published in 2016, was also discussed:

TERM	DEFINITION
Sex	Biological classification as female or male based on chromosomes, genitalia, and reproductive organs
Social construction	The process by which societal expectations of behavior become interpreted as innate, biologically determined characteristics
Gender	A socially constructed category addressing how people identify and act based on sex (e.g., men and women)
Sex/Gender	Combined term of sex and gender acknowledging that the discrete meanings of these terms are not easily separated in research and practice

Cis-sex/gender	An individual whose gender identity coincides with that individual's birth assigned sex/gender (e.g., a cis-man is often referred to as a "man")
Transgender or trans	An individual whose gender identity does not coincide with that individual's assigned gender at birth

Ms. Hardacker described the final inclusion criteria for the PLUS study:

- "Female Assigned At Birth (FAAB)"
    - Assumption: Uterus, Ovaries, Ova, short urethra (compared to male)
- + Female: Self-Identified
- = Cisgender female
- Cisgender: defined as a person whose gender identity is in alignment with their sex assigned at birth

PLUS will include sexual orientation and gender identity as a part of their demographics in all prospective studies. PLUS researchers focused on being intentionally inclusive and mindful of terminology. The PLUS Consortium is currently holding focus groups on bladder health under the research Study of Habits, Attitudes, Realities and Experiences (SHARE) protocol. The goal of this opportunity is to engage cis-gender women of all ages in a discussion about bladder health. The PLUS Loyola University Research Center was awarded an NIH Office of Sex and Gender Minority Research supplement to parallel the SHARE protocol to intentionally include all persons with a "short urethra" who are not cisgender and of all sexual orientations. This allows research access to the full spectrum of participants.

Ms. Hardacker concluded her talk with the following recommendations to the group and commented that traditional researchers who adopt these methods will have a better understanding of their study populations:

- Be clear about potential research participants and populations of interest
- Ask sex assigned at birth (SAAB) and sexual orientation and gender identity (SOGI) demographic information
- Use affirming language to include all gender identities and sexual orientations

Part II: Bladder Health and Bathroom Access in the Workplace

Bathroom Access — Current Issues in Occupational Health

Doug Trout, MD, MHS, NIOSH & Candice Johnson, PhD

Dr. Trout noted that he works at the National Institute for Occupational Safety and Health, a sister agency to OSHA. While OSHA is responsible for regulation

and enforcement of occupational health in the US, NIOSH is responsible for developing new knowledge in the field of occupational safety and health and transferring that knowledge into practice. OSHA standards set the guidance on sanitation standards in the workplace and the guidelines state that restrictions on bathroom access must be reasonable. However, the agency details different standards for migrant workers and manufacturing employees. Complaints from workers are evaluated on a case-by-case basis. Although workers may use OSHA as a recourse for bathroom access in the workplace, workers may also issue a complaint through the American Disability Act (ADA).

Workers may encounter several obstacles to bathroom access in the workplace, such as:

- Worksite has no bathroom
- Supervisors deny bathroom access
- Bathroom difficult to access
- Workers must clock out to use the bathroom (lost pay)
- Workers are too busy to use the bathroom
- Cleanliness, safety concerns prevent bathroom use

Workers often have medical conditions that require more frequent bathroom access such as bladder, bowel, prostate, gynecologic conditions, medication which causes more frequent urination, menstruation and pregnancy. Dr. Johnson presented research on the following occupational groups: teachers, poultry processing workers, migrant farmworkers, and transit workers. Many teachers must restrict fluid or leave children unattended to use the bathroom. When studying poultry processing workers, interviewers noted that 86% get fewer than 2 bathroom breaks per week and 80% are not allowed to take bathroom breaks when needed. Poultry processing workers noted that they wear diapers or urinate in their clothes to prevent harassment or bullying in the workplace. In the migrant farmworker population, interviewers discovered that workers have limited to no access to water or bathroom facilities. In addition, some employers may charge the workers for water or threaten to call immigration if a worker complains about lack of facilities. Another occupational group that suffers from lack of facilities or opportunities to use the restroom is transit workers. Many in this population are tasked with driving for extended periods of time without bathroom facilities.

Dr. Johnson presented two NIOSH research studies:

- The BD-STEPS Study, which includes data on the number of bathroom breaks at work per day, industry and occupation, UTI in pregnancy
    - Data not yet available

- The National Birth Defects Prevention Study, which includes data on occupational risk factors for UTI in pregnancy
    - No information on bathroom access
    - Link to O*NET for information on work environment
    - Industry and occupation, fluid intake

Dr. Johnson noted that occupational health research relating to bladder health could include 1) workers at risk, 2) coping strategies and health (holding behaviors, dehydration, mental health and well-being), and 3) effect on employment. When charged with what the research community can do to assist in these matters, Dr. Johnson noted that encouraging discussion among workers, employees, the public and the media is a beginning. Urination, defecation, and menstruation issues in the workplace are often not recognized or discussed. Another approach is to increase awareness about this public health problem among researchers. Researchers may then publish and present research as well as collect data.

Discussion

The group discussed partnership opportunities across their agencies. NICHD commented that they were interested in collaborating on lactation issues and occupational research. Dr. Markland noted that she will follow-up with Drs. Trout and Johnson in an offline discussion.

What do we know about occupational bathroom access and bladder health?

Alayne D. Markland, DO, MSc, University of Alabama at Birmingham

Dr. Markland opened her talk by discussing existing research on occupational bathroom access and bladder health. The number of women in the workplace has vastly increased over the last 50 years, and bathroom access (or lack thereof) may affect this population.

- Workforce participation by women
    - 38% in 1963 to 58% in 2012
    - Increase of 53%
- Working mothers in the workforce
    - 54% in 1962 to 71% in 2012
    - Increase of 30%
- Educational attainment (HS) by women
    - 48% in 1962 to 88% in 2012
    - Increase of 40%
- Top 3 common occupations for women:
    - Primary school teachers
    - Registered nurses
    - Administrative assistants

Dr. Markland discussed common considerations of toileting in the workplace: toilet access (number, variability for sex/gender, disability), toilet environment (cleanliness, privacy, supplies, & safety), workers' rights not clear (medical conditions, changing environments for clothes), permission and penalties, and access to fluids. Direct care workers, home healthcare workers, and family caregivers can also be subject to these restrictions and are among the populations to study.

Dr. Markland discussed the Marc Linder and Ingrid Nygaard book: "Void Where Prohibited." This focused on a policy review from a historical perspective and found:

- Associations between holding behaviors in the workplace and negative outcomes
    - Increased UTI rates
    - Increased adaptive behaviors
    - Increased medical costs
- Autonomy and Access issues exist in the workplace
    - "At will voiding"
    - Legislate vs educate

Institutional environments impact voiding behaviors and bladder health through: autonomy (physical condition), access to bathrooms, and adaptations (adjusting fluid intake, voiding without use of bathroom). This model can also apply to schools.

Urology researchers believe recurrent and sustained bladder holding behaviors might impair bladder function over time via:

- Increased bladder distention leading to decreased bladder contractility (detrusor muscle)
- Impaired sensation (neurologic)
- Impaired pelvic floor musculature (striated voluntary muscle)
    - Increased tone vs decreased ability

Teachers, nurses, swing shift workers, and nocturnal workers may develop issues from a urine production standpoint. More animal models are needed to support these research hypotheses as well as provide more research within these populations. A rapid evidence review by PLUS researchers showed:

- Comparing across occupational groups (3 studies, non-US):
    - Increase in UI (OR 6.9, 95% CI 5.66-8.47) and OAB (OR 1.7, 95% CI 1.6–1.8) for manual labor occupations compared to women in non-manual occupations (2 studies)
    - Increase in UI (OR 1.6, 95% CI 1.2-2.2) in sales/service compared to unemployed women (1 study)

- Holding hypothesis – nurses, teachers, and factory workers (7 studies):
    - Access – Delaying voiding while at work
    - Autonomy – Urinating with little or no need ("just in case")
    - Adaptive behaviors - Avoidance of public toilets, reducing fluid consumption*, and restricting fluid*

- LUTS contributes to workplace impairment (3 studies):
    - decreased productivity and performance

    - increased intent to leave work or change jobs
    - increased disability not workforce exit

Dr. Markland also discussed results of an analysis using data from the Boston Area Community Study (BACH):
2,789 women with complete data:

- 61% reported currently working for pay; 11% retirees, 10% disabled, 7% homemakers, and 7% unemployed
- Office and Administrative Support (n=510, 18%) and Service (n=866, 31%) - most common groups
- 63% of women reported any LUTS (range 54% to 82%)
- Women in Computing, Engineering, and Science (n=59) had increased overall LUTS (PR=1.3, 1.1-1.5), $p<0.05$
- Women in Healthcare (n=133), Education (n=415), and Unemployed women (n=140) – no changes in prevalence

Cross-sectional analysis findings included:

- LUTS varies across women by occupational groups,
- Women in manual, service, teaching, and nurses/healthcare occupations were not at higher risk in BACH – a finding not consistent with the existing literature,
- Occupation type (at the level available in BACH) may not be a good surrogate to support the holding hypothesis. There is wide variation in occupation types within each group, and
- The hypothesis may relate to UI or OAB but not broader LUTS.

In conclusion, Dr. Markland discussed next steps and future directions within the PLUS Consortium:

- Analysis of longitudinal BACH data
- Analysis of other existing data sources – e.g., NHANES
- Momentary ecological assessment: “Where You Go” Bladder App for Mobile Devices
    - Access
    - Autonomy
    - Adaptation

<u>Discussion</u>
Through the development of a mobile app, participants may take photos of the toileting environment and share experiences, attitudes, and beliefs. Dr. Bavendam noted that the goal is to gather data about individual preferences. GPS coordinates will help identify where participants use the bathroom. Dr. Markland also noted that deployed military and homeless populations are also at risk. Bathroom access and restrictions should be considered for these populations as well. Dr. Abbott commented about bathroom access on planes. Bathrooms are often very small and uncomfortable. Dr. Bavendam noted that research in this area is up and coming for the PLUS Consortium.

Ms. Norton provided an update on NIDDK initiatives related to self-management in urology.

- H3Men manuscript has been published: https://www.ncbi.nlm.nih.gov/pubmed/29199000
- An OBSSR-led manuscript is currently in review
    - solicited by *Translational Behavioral Medicine*.
    - highlights self-management research needs/opportunities at NIH, including information from NCI, NIDCR, **NIDDK**, NHLBI, & NINR.
- Self-management interest group formed:
    - Objectives:
        - Improve/share understanding of self-management research techniques?
        - Discuss application of self-management science to urologic research?
    - Activities/topics:
        - Discussion/feedback on grant applications
        - "Journal club" style discussion of recent studies
        - Strategies for maintenance of behavior change (Jan 5)
    - Meets approximately every other month
        - Next meeting: Friday, Jan 5: 12pm-1pm in Dem 2
        - All are welcome!

Agency Updates – Round Table

- Dr. Bañez noted that a draft AHRQ systematic review of nonsurgical treatment for UI conducted with PCORI would be available for comment. The commentary period is 45 days: https://effectivehealthcare.ahrq.gov/topics/urinary-incontinence-update/draft-report?hash=B91bR9ThrOV_T0wgEVEFwe2fM-Vx3pssvBjoToXxl6M
- Dr. Xie noted that Dr. Parker delivered an excellent and informative presentation. He also commented on the need for fundamental questions within the SGM population.
- Dr. Bavendam closed the meeting and thanked participants. The second NIDDK meeting on individualizing UI treatment will take place on Feb 1-2 at Natcher Conference Center on the NIH campus. To register: https://www.niddk.nih.gov/news/events-calendar/Pages/individualizing-treatment-urinary-incontinence-evolving-research-questions-research-plans-2017.aspx.

The next UICC meeting will be July 13th and will feature the following topics: urinary tract infections and research in nursing homes.

Meeting Adjourned