Public Research Summaries

From the PLUS Women's Bladder Health Research Consortium

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

A Program of the National Institutes of Health

Table of Contents

What is PLUS?

WHY WOMEN'S BLADDER HEALTH?

Bladder health. Lower Urinary Tract Symptoms (LUTS). These aren't topics girls and women discuss very often – among friends, with Mom, or even with their doctor. From childhood to menopause and beyond, bladder health is a concern for all women. As many as 40% of women and girls experience symptoms in their lifetimes.

Yet, too often women feel shame or embarrassment, and hide their symptoms – managing them alone and without the benefit of the latest information and treatments.

And, that's what PLUS is trying to change.

We are a group of researchers who work at nine universities across the United States. We understand that bladder health is an important topic that can affect women and girls in a lot of ways - and we don't fully understand what contributes to good or poor bladder health.

OUR RESEARCHERS

PLUS is supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH).

Our team includes researchers from over 50 fields. By sharing methods and expertise among researchers from medicine, nursing, epidemiology, biostatistics, social work, community health and other areas, PLUS hopes to greatly improve prevention strategies for bladder health.

"PLUS is about moving beyond the laboratory and establishing a partnership with women across the United States – learning from them and sharing the latest information on bladder heath."

-Plus Investigator

PLUS Research Studies

The PLUS consortium began in 2015 and ends in 2025. Below is a summary of a few of our studies, but our research includes far more than what's listed here.

To date, we have written 66 papers for scientific journals, with more still to come. On the following pages, you will find summaries of specific research articles, explaining the main findings from each paper.

These research summaries and a printable version of this report can be found at **www.plusconsortium.umn.edu/research-summaries**.

STUDY	DETAILS	RESULTS
Study of Habits Attitudes Realities and Experiences (SHARE)	We conducted focus groups with girls and women aged 11-93 years. Focus groups were discussion sessions with groups of similar aged participants.	Participants told us about experiences, perceptions, beliefs, knowledge, and behaviors related to bladder health. We heard perspectives from women and girls from many identities, lived experiences, and in different stages of life.
Bladder Health Experiences and Opinions of Sexual and Gender Minorities (SHARE MORE)	We conducted additional focus groups with adults who identified as queer, bisexual, lesbian, gay, gender queer or nonconforming, trans masculine, or another gender identity.	Participants shared unique experiences and challenges around bathroom use that they face because of their identity, which may have important consequences for bladder health.

STUDY	DETAILS	RESULTS
Clarification of Language, Evaluation And Refinement of questions (CLEAR) and Validation of Bladder Health Instrument for Evaluation in Women (VIEW)	We developed a survey to learn about bladder health. We tested our survey to make sure the questions made sense and matched data collected in a clinical visit.	Our bladder health survey is a thorough and reliable way to learn about bladder health in groups of adult women. The survey will be used in the RISE FOR HEALTH Study and future research studies as well.
RISE FOR HEALTH	We invited women from across the country to complete a survey every year for 3 years. We asked a smaller number of these women to come in for a clinical visit.	This is the first study to describe what bladder health looks like and how it changes over time for a large group of women from different backgrounds, ages, experiences and identities. We also learned about many factors that we think might be related to bladder health.

Study Results

Background Research: Laying the Groundwork for PLUS Studies

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Assessing bladder function in healthy female children and adolescents using non-invasive tests

Why did we do this study?

Lower urinary tract symptoms, for example leaking pee or a sudden need to pee, are common in children and adolescents. These can lead to bladder problems later in life. Health care providers use several tests to learn about how well the bladder is working in children and adolescents. They prefer to use tests that don't break the skin or go inside the body (non-invasive tests). To help understand what these test results mean for individual children and adolescents, we need a better understanding of what range of results are typical in healthy kids.

What did we study?

As a first step to understanding the range of normal results for different bladder tests, we reviewed articles from previous research studies. We found 10 studies that had information about the range of results in female children and adolescents aged 5 to 18 years.

We calculated averages and summarized the ranges for seven tests used to measure bladder function.

What did we learn?

1. Voiding frequency (how often the children peed) was not reported by any of the 10 studies.
2. There were large differences in the ages reported in the 10 studies. This makes it harder to combine results and come to strong conclusions.
3. On average, girls and young women in the included studies:
   Release about 7 ounces of pee each time they pee. That's a little more than half a can of soda.
   Have about 2 teaspoons of pee left in the bladder right after they pee.
   Release about 3/4 of an ounce of pee per second at the fastest point of peeing.
   Release a little less than half an ounce of pee per second on average over the whole time they pee.
   Take about 7 seconds to reach the fastest point of peeing.
   Take about 16 seconds to complete peeing.

What was the overall conclusion?

We were able to calculate averages and ranges for seven important tests of how well the bladder is working. However, due to the small number of studies, and the wide range of ages, we cannot say for sure whether the averages and ranges we found reflect typical or healthy bladder function. We recommend that future research collect more data on these tests to help understand typical and healthy values for specific age groups.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu

To learn more, see the full article: Meister, M., et al.; Non-invasive bladder function measures in healthy, asymptomatic female children and adolescents: A systematic review and meta-analysis. J Pediatr Urol. 2021 Aug;17(4):452-462. Link to the full article: DOI: 10.1016/j.jpurol.2021.04.020

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Research Article Summary: Standardized and noninvasive bladder function measurements in healthy women: A systematic review

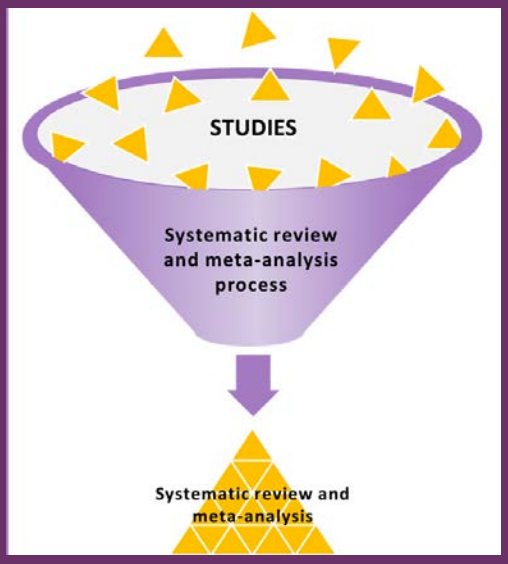
Purpose

To define the range of normal bladder function using noninvasive tests by summarizing bladder function in healthy women

What we studied

PLUS researchers identified and analyzed 24 studies of bladder function tests, published in English, that included results from 3090 healthy women ages 18-91 years.

The types of tests were: frequency of urinating, urine volume from urinating, and remaining urine volume in the bladder after urinating, and uroflowmetry.



Definitions:

- Systematic review - a type of review that is based on a clear question, identifies all relevant studies, appraises their quality, and summarizes the evidence.
- Invasive tests – in general, test with a puncture or incision to the body.
- Non-invasive tests - test with no incision to the body.
- Normal reference range – the range of test results are within normal or healthy function
- Remaining urine volume - the amount of urine retained in the bladder after peeing
- Uroflowmetry – a diagnostic test to assess how well the urinary tract functions.

What we learned

We found that there was a wide range of what was considered normal in urination tests of a healthy bladder. This wide range could be due to how the studies were conducted or differences in women's habits and behaviors. More information is needed to understand the reasons for this wide range.

To learn more, please see the published article:

Wyman JF, Zhou J, Yvette LaCoursiere D, Markland AD, Mueller ER, Simon L, Stapleton A, Stoll CRT, Chu H, Sutcliffe S. Normative noninvasive bladder function measurements in healthy women: A systematic review and meta-analysis. Neurourol Urodyn. 2020 Feb;39(2):507-522. doi: 10.1002/nau.24265. Epub 2020 Jan 9.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

plus

PREVENTION OF LOWER URINARY TRACT SYMPTOMS

A Research Consortium of the National Institutes of Health

How frequently do healthy women pee?

Purpose

To guide bladder health awareness and treatment programs, we need to know how often women "pee." Little is known about what is normal for daytime and nighttime peeing.

What did we do? Who was in the research?

We analyzed information that had been collected by the Boston Area Community Health (BACH) survey of 2534 women ages 31 to 84 years to calculate how often healthy women pee (the range of **healthy pee frequencies**) during daytime and nighttime. We also looked at whether frequency of peeing in women differed by race, ethnicity, and volume of water/fluid they drank (fluid intake).

Key findings

- On average, women pee 5 times during the day and 1 time during the night. The range was 2-10 times during the day and 1 - 4 times at night.
- Women ages 45-64 years reported a greater number of *daytime urinations (peeing)* than those aged 31-44 years. Women 65+ years reported a greater number of *nighttime urinations* than those under age 65.
- Black women reported less daytime urination and more nighttime urination than white women.
- Women who consumed less than 49 oz of fluids daily reported fewer daytime and nighttime urinations than those who drank 50-74 oz. However, drinking more than 75 oz increased urination frequencies by only a small amount.
- Future research is needed about urination frequencies, including the reasons for differences across racial and ethnic identities, and whether fluid intake makes a difference in bladder health.

20 oz 32 oz 64 oz

For more information, please see the published article:
Wyman JF, Cain CH, Epperson CN, Fitzgerald CM, Gahagan S, Newman DK, Rudser K, Smith AL, Vaughan CP, Sutcliffe S; Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. Urination Frequency Ranges in Healthy Women. Nurs Res. 2022 Sep-Oct 01;71(5):341-352.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

IT'S ABOUT TIME: THE BURDEN OF LOWER URINARY TRACT SYMPTOMS AMONG WOMEN

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

WHY?

This study was conducted to explore how women cope with ongoing urine leakage, frequent or urgent need to pee, and waking at night to pee.

HOW?

50 women participated in one-on-one, in person interviews about their bladder symptoms, how long they have had them, and how they manage them.

WHAT WE LEARNED

- **Chronic urinary tract symptoms disrupt women's lives. Women with these symptoms feel they have to stay alert to situations where they may not be able to manage their symptoms.**
- **Women described how they organize their daily schedules around their bladder needs, anticipating problems and avoiding certain places and activities where problems could occur.**

WHAT DOES IT MEAN FOR YOU?

When talking with your medical provider, it's important to include your history of bladder problems, and how they disrupt your everyday life. Your medical provider can treat physical symptoms but also help you reduce feelings of isolation and powerlessness. You don't have to handle it alone!

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Williams, Beverly Rosa et al. "It's about time: The temporal Burden of Lower Urinary Tract Symptoms Among Women" Urology (2020): 277-289

Occupation and lower urinary tract symptoms in women

OUR QUESTION

Can limited access to bathrooms at work be related to lower urinary tract symptoms (LUTS) in women?

WHAT WE DID

We reviewed data from 1990-2017 to **see if there is a relationship between a woman's job and whether or not she experiences lower urinary tract symptoms** (inability to hold urine, overactive bladder, urinary tract infections).

Specific job types were examined. We looked at women who are **nurses, midwives, healthcare workers, military personnel, teachers, and others.**

WHAT WE FOUND

- More studies should be done, especially those related to bladder habits at work.
- Women with manual jobs may have more physical demands at work like heavy lifting or strenuous activity which may cause urine leakage. These women also may have limited access to toilets during their work day.
- Women in service and retail occupations may not have enough time to pee due to high-paced job demands.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

For more information visit:

https://doi.org/10.1002/nau.23806

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Markland, Alayne, et al. "Occupation and lower urinary tract symptoms in women: A rapid review and meta-analysis from the PLUS research consortium." Neurourology and urodynamics 37,8 (2018): 2881-2892.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Research Article Summary:

Sexual Health and Bladder Health Among Young Women: Is there a Connection?

We studied data from young women in the United Kingdom to learn how sexual health may relate to bladder problems.

Why?

- Many young women wonder whether their sexual health is related to their bladder health.
- This study explored the connection between sexual health and bladder problems among women ages 15-19.

Key findings:

- Having sex by age 17, especially for those who have had sex with 3 or more partners, was linked to a higher chance of having bladder problems at age 19. BUT: The relationship was weaker for those who used condoms during sex.
- Using birth control pills by age 17 was also linked to the risk of having some bladder problems at age 19, but this might have been related more to sexually transmitted infections than the birth control itself.

More Information

- This study looked at survey data from young women in the UK to answer the question of whether or not bladder health and sexual health are related.
- 1,941 young women were asked to fill out confidential surveys when they were 15, 17, and 19 years old.
- They answered questions about whether they had sex, used birth control pills and/or condoms, and how many people they had sex with.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

The complete article by Deepa Camenga et al., “Sexual Health Behaviors by Age 17 and Lower Urinary Tract Symptoms at Age 19: PLUS Research Consortium Analysis of ALSPAC Data” *Journal of Adolecent Health (2023)*

To read the full research article: https://doi.org/10.1016/j.jadohealth.2022.12.019

Research Article Summary

School toileting environment, bullying, and lower urinary tract symptoms in a population of adolescent and young adult girls

We studied data from 3,962 teenage girls to learn how school bathrooms affect toilet behavior and risk for bladder problems

Why?

- Teenagers spend a large part of their day in school. A lack of privacy, safety, cleanliness, and wait times may affect whether girls use school bathrooms, how oftenthey pee, or if they have accidents.
- Understanding how school bathrooms affect bladder health is important to preventing and treating bladder symptoms - such as daytime urine leaking, urgent need to pee, frequent peeing, low amount of pee, peeing at night, bed wetting, and holding - in teenagers and young adults.

Key Findings

Physical and social conditions of school bathrooms affect teenage girls' toilet behaviors

- Girls are more likely to hold in pee until they feel like they will burst, if toilets:
  - Are dirty or in bad condition
  - Lack privacy
  - Don't have toilet paper, soap, or hand dryers or towels
  - Have long lines
- Girls who fear bullying in the bathroom are most likely to hold it.

Bathroom conditions are associated with bladder symptoms, such as those listed above

- Physical and social bathroom conditions were assciated with at least one bladder symptom at age 13.
- The fear of being bullied in the bathroom was the one bathroom condition associated with all bladder symptoms, except bedwetting.

Conditions in school bathrooms in the early teens may be associated with bladder symptoms at the start of adulthood

- Girls who reported that school bathrooms were dirty or lacked privacy or soap at age 13 were more likely to have bladder filling symptoms, such as bladder pain, at age 19.

More Information

- Data were collected as part of the Avon Longitudinal Study of Parents and Children (ALSPAC).
- Respondents were asked to select from seven checkboxes about their school toileting environment when they were 13 years old: (1) toilets are dirty or in bad condition, (2) don't have any privacy, (3) don't have toilet paper, (4) don't have soap, (5) don't have hand dryers or towels, (6) child is likely to be bullied at toilets, and (7) there is always a queue at toilets.
- Questions about lower urinary tract symptoms (LUTS, e.g., daytime urinary incontinence, urgency, frequent urination, low voiding volume, nocturia, bedwetting, and holding behavior) were asked when children were 13 and 19 years old.
- Analyses for this study used data from 3,962 female children who reported at least one holding behavior variable (holding urine when the urge to urinate is felt) and associated behaviors (e.g., fidgeting) at age 13 or one LUTS variable response at age 19.
- Multiple imputation was used to handle missing data.
- Multivariate logistic regression methods were used to examine associations between risk factors and LUTS, controlling for potential confounders.
- At age 13, analyses were cross-sectional; longitudinal analysis of LUTS at age 19 only included participants without LUTS at age 13.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

The complete study by DA Shoham, Z Want, S Lindberg, et al., "School toileting environment, bullying, and lower urinary tract symptoms in a population of adolescent and young adult girls: Preventing Lower Urinary Tract Symptoms Consortium analysis of Avon Longitudinal Study of Parents and Children," in *Urology*, 15 Jul 2020, S0090-4295, vol. 20, pp.30827-X.

VIEWS OF NORMAL BLADDER FUNCTION AMONG WOMEN EXPERIENCING LOWER URINARY TRACT SYMPTOMS

This study was done to better understand how women with lower urinary tract symptoms see healthy bladder function.

HOW WAS THIS DONE?

Our team reviewed data from 50 adult women with lower urinary tract symptoms were interviewed regarding their thoughts on normal bladder function.

WHAT DID WE LEARN?

Normal bladder function was seen as both the **absence of symptoms** and **absence of worry**. Women generally found these aspects most important for a healthy bladder:

- Regularly urinating
- Being able to hold urine when necessary
- Controlling the urge to urinate
- Experiencing no dribbling after urination.
- Being able to live life and perform daily activities without any bladder concerns

HOW IS THIS INFORMATION USEFUL TO YOU?

It is important for healthcare providers to understand what "normal" bladder function typically means to women. Having a better idea of this will improve conversations between women and their clinicians.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

FOR MORE INFORMATION VISIT:
https://doi.org/10.1016/j.urology.2020.08.021

Burgio, Kathryn L., et al. "Views of normal bladder function among women experiencing lower urinary tract symptoms." Urology 150 (2021): 103-109.

The PLUS Consortium's Approach to Bladder Health

The Prevention of Lower Urinary Tract Symptoms (PLUS) Consortium is a group of 9 research universities supported by the National Institutes of Health. This article describes a new approach to study how to improve women's bladder health.

What is the purpose of PLUS?

PLUS is collecting the information needed to design bladder health prevention strategies for girls and women. Prevention strategies are activities and programs designed to keep people healthy and prevent health problems before they start. Although prevention strategies have been successful in many areas (e.g., tobacco use, cancer, auto safety), they are relatively new in women's bladder health.

We have assembled a research team from across many fields including medicine, nursing, public health, and the social sciences. We are involving community members in planning so that our research is relevant to the people we hope to help.

Collecting this information involves figuring out which questions to ask, and the best way to ask them. To do this, we will use a variety of research methods, such as surveys, focus groups, and clinical tests.

We are collecting information about what is most likely to create bladder health problems, and what helps to protect women from these problems. Once we have that information, will be able to create programs and activities to promote bladder health for girls and women in the future.

Why is PLUS important?

PLUS takes a new approach to women's bladder health research. Rather than focusing only on symptoms or problems that already exist, PLUS takes a wider view of bladder health. We want to explore bladder health beyond just biology, including how it is related to social, economic, environmental, and other aspects of how girls and women live throughout their lives.

Medical professionals, such as nurses and primary care providers, can have an important role in promoting bladder health and preventing lower urinary tract symptoms. PLUS hopes to provide them with the information needed to do this important work.

To learn more please read the research article:

Smith, A. L., Rickey, L. M., Brady, S. S., Fok, C. S., Lowder, J. L., Markland, A. D., Mueller, E. R., Sutcliffe, S., Bavendam, T. G., Brubaker, L., & Prevention of Urinary Tract Symptoms (PLUS) Research Consortium (2021). Laying the Foundation for Bladder Health Promotion in Women and Girls. Urology, 150, 227–233.

Link to article:

https://doi.org/10.1016/j.urology.2020.03.011

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu

Community Engagement in the Prevention of Lower Urinary Tract Symptoms (PLUS) Consortium

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

This paper describes the main lessons and challenges of implementing community engagement (CE) in PLUS, along with recommendations for other research groups in the future.

What is PLUS?

PLUS began in 2015 to study how to improve bladder health in adult and adolescent female populations. The work started with research focusing on personal experiences with bladder health.

What is CE in Research?

It's the process of working alongside community members (non-scientists) to conduct research. CE can be a way to address racism and fairness in science. CE tries to make sure research studies include diverse study teams and participants and that the research addresses the needs of the community.

What is the purpose of CE in PLUS?

PLUS incorporated CE as a way to improve the quality and relevance of their research and actively fight against racism in science (antiracism).

How was CE Incorporated?

- Using CE in PLUS involved several different stages of action.
- First, there was a planning process to create a vision for CE in PLUS.
- Then, PLUS members worked on building momentum by raising awareness and making sure consortium members felt comfortable, committed, and had the necessary skills for inclusive research.
- After that, PLUS incorporated these processes into the structure of the consortium by holding more informal discussions and CE information sessions to build collaborative relationships with community partners.
- Once relationships had deepened, individuals were invited to be Rapid Assessment Partners, where they would directly collaborate to address issues over time.
- Finally, CE was developed, implemented, and evaluated in all PLUS research to bring the vision to life. This was an ongoing process throughout PLUS research.

Takeaways:

- CE means making community voices heard, and being dedicated to creating and sticking to partnerships that benefit everyone involved.
- It's important to recognize and use the strengths of local communities because working together makes us stronger.
- The central principles of CE oppose racism to help build a more inclusive, antiracist research environment.

To learn more, please see the full article:

James, Aimee, et al. "Building Community Engagement Capacity in a Transdisciplinary Population Health Research Consortium." Journal of Community Engagement and Scholarship. 2024 Apr;16(2):10

Link to full article:

https://jces.ua.edu/articles/10.54656/jces.v16i2.496

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Study Results

Study of Habits, Attitudes, Realities, and Experiences (SHARE)

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Research Article Summary

Social Processes Informing Toileting Behavior Among Adolescents and Adult Women: Social Cognitive Theory as an Interpretive Lens

We asked women of all ages about how they go to the bathroom, or their "toileting behavior."

Why?

- Previous research has shown that women learn toileting behavior through social processes.
- More research can show how these social processes work to influence toileting behavior.
- Understanding the way women learn toileting behavior can help identify how to best teach new, healthy toileting behaviors.

Key Findings

Observation was the most important social process in forming toileting behavior.

Observing others

- Women reported learning toileting behavior from close relationships, such as family.
- Women learn normal toileting behavior by observing and comparing the toileting behavior of peers.
- Social behaviors around using the bathroom were also learned from peers, including norms around bathroom access.

Being observed

- Observations from close relations were frequently seen as teaching or guiding toileting behaviors.
- Observation by supervisors, teachers, or peers were frequently seen as controlling toileting behaviors.
- Being observed made women feel embarrassed, uncomfortable, or self-conscious often to the point of avoiding the bathroom.

More Information

- Forty-four focus groups were conducted with 360 female participants at 7 sites across the US.
- Participants were 11 to 93 years old. Women of similar ages were grouped together. Eligibility criteria to participate included: 11 years old or older; assigned female at birth; not pregnant; English- or Spanish-speaking; able to provide written informed consent; and did not have any physical or mental condition that would affect their ability to be in the study.
- Participants were diverse in terms of race, ethnicity, education, socioeconomic status, physical/health conditions, lower urinary tract symptom (LUTS) status, geography (urban/rural), and language.
- Participants were asked about healthy bladder beliefs/attitudes, bladder knowledge acquisition, experience with LUTS and care seeking, terminology, and public health messaging. The conversations were recorded and transcribed.
- Reserachers read and coded the transcripts to identify themes for how women talk about bladder health and function.
- Findings were reviewed by community members and other stakeholders.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at **www.plusconsortium.umn.edu**.

The complete article by J Hebert-Beirne, DR Camenga, AS James, et al., "Social Processes Informing Toileting Behavior Among Adolescent and Adult Women: Social Cognitive Theory as an Interpretive Lens," can be found in *Qualitative Health Research,* 2021, vol 31, issue 3, pp 430-442.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

EVERYBODY GOES TO THE BATHROOM.

But do we really go **ALONE**?

Turns out we don't!

We held small discussion groups with 360 women and girls of all ages from around the country to learn more about their experiences with **bladder health**.

We found that behavior around going to the bathroom is a **highly social process** that is affected by observing the **bathroom habits** of others or by having our own behavior observed.

- social reasons to go to the bathroom
- avoiding water to limit trips to the bathroom
- your posture on the toilet
- which bathrooms you use or avoid
- length, frequency, timing of trips to the bathroom
- how long you "hold it" before going to the bathroom
- our feelings about going to the bathroom

BATHROOM HABITS?

HOW ARE BATHROOM HABITS **SOCIAL?**

WHAT'S SO SOCIAL ABOUT GOING TO THE BATHROOM?

By social, we mean a process that involves other people.

LIKE WHEN YOU TAKE OTHER PEOPLE WITH YOU TO PEE?

Not exactly, though that IS a part of it! We mean watching how others use the bathroom, whether we realize it or not.

BUT I DON'T WATCH PEOPLE PEE!?

You don't have to directly observe to notice! Discussion group participants talked about direct and indirect ways of learning to use the bathroom, including normal and abnormal ways to use the bathroom.

AND OTHER PEOPLE WATCH ME PEE TOO?

Sort of. Participants reported how their bathroom habits were often observed and controlled by authority figures at all ages.

AT ALL AGES? ARE YOU SURE? WHAT KIND OF AUTHORITY FIGURES?

Unfortunately so. Teens reported how teachers restricted bathroom use in school, but adults also reported how work pressures or bosses would do the same.

WOW, THAT SOUNDS REALLY DIFFICULT.

Absolutely! Many participants reported feeling embarrassed, self- conscious, or even avoiding the bathroom because of this!

SO WHAT?

Bladder health is important for all ages. Symptoms may show later in life, but **bladder problems can start early**.

If bathroom habits are social, then **people can learn healthy behaviors the same way they learned their current behaviors**. Once PLUS has more information on healthy and unhealthy habits, we will use these channels to share healthy bathroom habits!

Remember: **everybody goes!** Normal bodily functions like peeing are NOT something to be ashamed of!

Adapted from Hebert-Beirne J, Camenga DR, James AS, Brady SS, Newman DK, Burgio KL, Kane Low L, Hardacker CT, Gahagan S, Williams BR. Social Processes Informing Toileting Behavior Among Adolescent and Adult Women: Social Cognitive Theory as an Interpretative Lens. Qual Health Res. 2021 Feb;31(3):430-442.

Research Article Summary: "I never knew anyone who peed on themselves on purpose: Exploring adolescent & adult women's lay language and discourse about bladder health and function"

We asked women of all ages how they speak about their bladder health with others

Why?

- The general public and healthcare workers use different words to talk about bladder health
- Sometimes the same words mean different things to the general public and to healthcare workers, which can be confusing
- A better, shared understanding of the words women use to discuss bladder health will help prevent problems and improve care efforts

Key Findings

Women use everyday language to describe bladder function

- *Pee is the most common term women use*
- *Urinate is the most common medical term women use -- if they use a formal word*

The words women use reflect who they are talking to and have changed over time

- *Women change how they talk about going to the bathroom based where they are (home, school, work, social event) and the people around them (family, friends, co-workers)*
- *Terms have changed - from "going to the ladies' room/to powder my nose" to "going to the bathroom/to pee"*

Women choose words that express how they feel about the problems they have peeing and how they are trying to become comfortable with those problems

- *Women use their own words to describe what they feel or experience -- not medical names*
- *They use words that help them minimize how severe or frequent their symptoms are*
- *The words women choose help them feel less blame or concern about their symptoms, such as saying "leaking" or "accident", not "urinary continence"*

Women seek help from, share experiences with, and give advice to family and friends

- *Women give support and help through stories, their own experiences, and lessons learned*

More Information

- Forty-four focus groups were conducted with 360 female participants at 7 sites across the US.
- Participants were 11 to 93 years old. Women of similar ages were grouped together.
- Eligibility criteria to participate included: 11 years old or older, assigned female at birth, not pregnant, English- or Spanish-speaking, able to provide written informed consent, and did not have any physical or mental condition that would affect their ability to be in the study.
- Participants were diverse in terms of race, ethnicity, education, socioeconomic status, physical/health conditions, lower urinary tract symptom (LUTS) status, geography, (urban/rural), and language.
- Participants were asked about healthy bladder beliefs/attitudes, bladder knowledge acquisition, experience with LUTS and care seeking, terminology, and public health messaging. The conversations were recorded and transcribed.
- Researchers read and coded the transcripts to identify themes for how women talk about bladder health and function.
- Findings were reviewed by community members and other stakeholders.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at **www.plusconsortium.umn.edu**

The complete article by BR Williams, J Nodora, DK Newman, et al., "I never knew anyone who peed on themselves on purpose: Exploring adolescent and adult women's lay language and discourse about bladder health and function", can be found in ***Neurourology and Urodynanmics -*** 2020, vol 39, pp 225-236***.***

Research Article Summary: U.S. Adolescent and Adult Women's Experiences Accessing and Using Toilets in Schools, Workplaces, and Public Spaces

We asked women of all ages to share their experiences accessing toilets outside of their homes

Why?

- Access to clean, safe toilets is important for women
- Little research has studied women's access to clean, safe public toilets in the United States
- A better understanding of how women access toilets can help promote bladder health

Key Findings

"**Gatekeepers**" - people who control when someone can use the toilet in a school, workplace, or other public place - may limit access to toilets

- *Teachers may control when their students are allowed to use the toilet*
- *Managers may limit when workers can take toilet breaks*
- *Stores may require people to buy something before using the toilet*

Men and women have different access to public bathrooms

- *Women wait in longer lines for public toilets than men – possibly due to*
  - *Their periods*
  - *More complicated clothing*
  - *More peeing symptoms*
  - *Need for more privacy when*
  - *using the bathroom*

Women may not use the toilet **due to a commitment and focus on their work**

- *They put more importance on school and work responsibilities than their need to pee*

Women avoid public **toilets that aren't clean**

- *Toilets that aren't in stores or restaurants, such as porta potties, parks, and rest stops, are seen as less clean*

More Information

- Forty-four focus groups were conducted with 360 female participants at 7 sites across the US.
- Participants were 11 to 93 years old. Women of similar ages were grouped together. Participants were 11 years old or older, assigned female at birth, not pregnant, English- or Spanish-speaking, able to provide written informed consent, and did not have any physical or mental condition that would affect their ability to be in the study.
- Participants were diverse in terms of race, ethnicity, education, socioeconomic status, physical/health conditions, lower urinary tract symptom (LUTS) status, geography(urban/rural), and language.
- Participants were asked about healthy bladder beliefs/attitudes, bladder knowledge acquisition, experience with LUTS and care seeking, terminology, and public health messaging. The conversations were recorded and transcribed.
- Researchers read and coded the transcripts to identify themes related to accessing toilets in schools, workplaces, and public spaces.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at **www.plusconsortium.umn.edu.**

The complete study by DR Camenga, SS Brady, CT Hardacker, et al. , "U.S. Adolescent and Adult Women's Experiences Accessing and Using Toilets in Schools, Workplaces, and Public Spaces", can be found in the ***International Journal of Environmental Research and Public Health,*** 2019 – volume 16, p. 3338.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

NEED FOR PUBLIC HEALTH MESSAGING RELATED TO BLADDER HEALTH FROM ADOLESCENCE TO ADVANCED AGE

Our research on women's bladder health has shown the need for prevention strategies, public health messages, and additional guidance for organizations that support bladder health.

WHY ?

The purpose of this study was to explore adolescent and adult women's views on the importance and usefulness of public health messages on bladder health.

METHODS

We conducted focus group discussion with 360 girls & women about their thoughts on public health bladder messages.

WHAT WE LEARNED

Women& girls across all age groups agreed that they want and need more information about the bladder, as there are currently not enough reliable resources.

Participants recommended education for the general public, especially parents and teachers who control bathroom access.

Participants felt that bladder health information helps women better understand bladder problems and take action to prevent them.

Kathryn L. Burgio, PhD,1,2 Shayna D. Cunningham, PhD,3 Diane K. Newman, DNP,4 Lisa Kane Low, PhD, CNM,5 Jesse Nodora, DrPH,6 Terri H. Lipman, PhD, CRNP,7 Shelia Gahagan, MD, MPH,8 Heather Klusaritz, PhD, MSW,4 Aimee S. James, PhD, MPH,9 Leslie Rickey, MD, MPH,10 Kimberly S. Kenton, MD,11 Jeni Hebert-Beirne, PhD, MPH,12 Beverly Rosa Williams, PhD,1 and The Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

U.S. ADULT WOMEN'S BELIEFS AND ASSUMPTIONS ABOUT BLADDER HEALTH & FUNCTION

In this study women shared their thoughts about how the bladder works and what makes it healthy.

WHAT WE DID

Women of different ages, races, & ethnicities from across the U.S. took part in focus group discussions about bladder health.

WHAT WE LEARNED

The women were not sure about how the bladder worked but thought bladder health was part of overall health.

They also felt some bladder health problems were unavoidable such as the effects of getting older on bladder function.

They believed that some aspects of bladder health were under their control such as eating healthy foods, drinking enough fluids, being physically active, and having bathroom hygiene.

Williams BR, Burgio KL, Hebert-Beirne J, James A, Kenton K, LaCoursiere DY, Rickey L, Brady SS, Kane Low L, Newman DK; Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. A multisite focus group study of US adult women's beliefs and assumptions about bladder health and function. Neurourol Urodyn. 2022 Sep;41(7):1590-1600

PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Research Article Summary: Women's Toileting Behavior and Bladder Health

Why did we do this study?

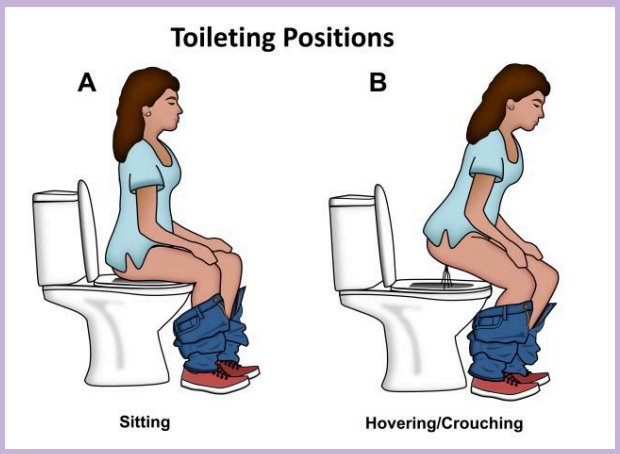
To learn about the ways in which women's toileting behaviors may be related to their bladder health

What did we do?

360 cisgender women ages 11 to 93 participated in focus groups (guided discussions). They also answered survey questions about toileting habits, LUTS and bladder health.

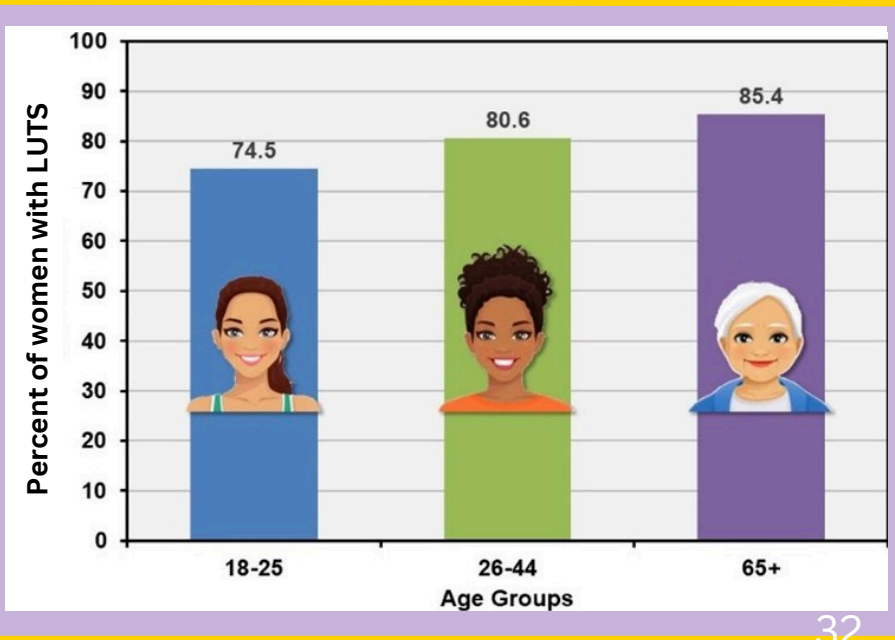
Definitions:

- Cisgender: a person whose gender identity matches with the sex registered for them on their birth certificate; not transgender.
- Voiding: urinating or peeing.
- Toileting behavior: habits that women follow when peeing. For example: sitting on the toilet (A) or standing over toilet (B); waiting to pee; peeing before feeling the need to pee; not using certain bathrooms.
- Bladder health: physical, mental, and social well-being related to bladder function.
- Lower Urinary Tract Symptoms (LUTS): Bladder symptoms like needing to pee immediately, peeing too often, urine leaks, waking up to pee at night, not fully emptying the bladder, and urinary tract infections.



What did we learn?

- **At least 3 out of every 4 women in the focus groups had at least one LUTS symptom. More women reported LUTS as the age groups went up (see figure to the right).**
- **More older women than younger women said they peed before feeling the urge to pee .**



What did we learn? - continued

- Most women in the youngest two age groups (18-25, 26-44) said they hold or put off peeing. Fewer women in the older age category (65+) said they delay peeing.
- All women preferred to pee at home, but Black and Hispanic women reported this preference more often compared to White women.
- Women who reported behaviors like peeing before feeling the urge, holding, straining, or hovering over the toilet when away from home were more likely to report bladder symptoms (LUTS). However, we can't know from this study alone if these behaviors *caused* the LUTS.

What's next?

- More research is needed about how access to public toilets affects toileting habits and bladder health, including in workplaces and other places women spend time.
- Our research suggests that some differences stem from systemic racism and discrimination towards women of color through differences in access to public toilets. More information is needed to understand this better.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

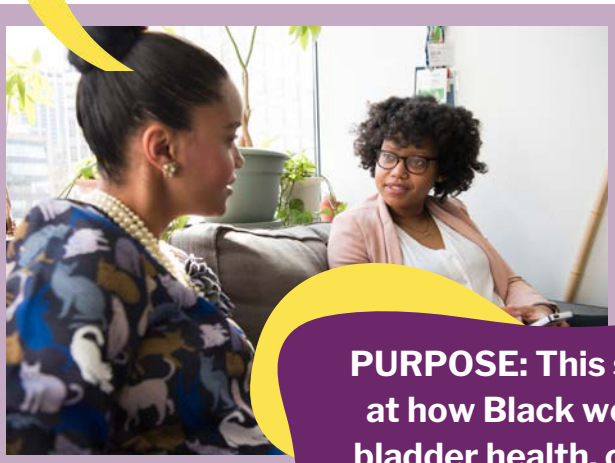
To learn more, please see the published article:

Newman DK, Burgio KL, Cain C, Hebert-Beirne J, Low LK, Palmer MH, Smith AL, Rickey L, Rudser K, Gahagan S, Harlow BL, James AS, Lacoursiere DY, Hardacker CT, Wyman JF; Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. Toileting Behaviors and Lower Urinary Tract Symptoms: A Cross-sectional Study of Diverse Women in the United States. Int J Nurs Stud Adv. 2021 Nov;3:100052.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

BLACK WOMEN'S PERSPECTIVES ON BLADDER HEALTH

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health



PURPOSE: This study looks at how Black women view bladder health, considering their environment and experiences over time.

WHAT WE DID

We analyzed data from six SHARE (Study of Habits Attitudes Realities and Experiences) focus groups with women who identified as Black or African American. Participants highlighted how race and gender influenced their perspectives on bladder health.

WHAT WE LEARNED

PARTICIPANTS DISCUSSED DISCRIMINATION AND:

- **Medical Care**: Some participants faced discrimination when seeking medical care, making it hard to get quality treatment.
- **Barriers to Access**: Rules in schools and workplaces limited access to bathrooms.
- **Stereotyped Caregiving Roles**: Expectations about caregiving responsibilities for women affected participants own health.
- **Lack of Reliable Info:** Participants felt they hadn't gotten enough reliable information about bladder health, especially as children.
- **Other Health Conditions**: Participants other health conditions affected or worsened their bladder health. This may be related to the stress of experiencing chronic racism and discrimination.

Programs to fix the barriers Black women face are crucial to improving bladder health.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

To learn more, see the research article:

Williams, Beverly R., et al. Black women's perspectives on bladder health: Social-ecological and life course contexts. Neurourology and Urodynamics 2024 Apr;43(3):849-861.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

WHAT DO YOUNG WOMEN THINK ABOUT BLADDER HEALTH?

PURPOSE

Bladder problems can have a big effect on young women's health and daily lives. This study wanted to find out what pre-teen and teen young women know and believe about bladder health.

WHAT WE DID

We held focus group discussions with adolescent women aged 11-17 across the US to learn what they know about bladder health.

WHAT WE LEARNED

- Many adolescent women want to learn more about how their bladder works.
- Adolescent women know that drinking enough water is important for bladder health.
- They also know that using the bathroom when they need to pee is important.
- Some avoid using school bathrooms due to cleanliness or classroom rules.
- Many worry that they will be embarrassed when peeing, for example because of sounds or smells, but they also know it is normal to have to pee.

WHAT'S NEXT?

This information will help us develop education, programs, and policies to improve bladder health for young women.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

To learn more, see the research article:

Camenga DR, et al; Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. Bladder Health Knowledge, Attitudes, and Beliefs among US Adolescent Women. J Pediatr Adolesc Gynecol. 2024 Oct 5:S1083-3188(24)00299-7. https://www.sciencedirect.com/science/article/pii/S1083318824002997?via%3Dihub

Women's Knowledge of Bladder Health: What Have We Learned So Far?

"I didn't know any of these things could happen **until they happened to me** and now, I heard other people's stories"

What did we do?

We examined data from our PLUS focus groups with adolescent and adult women aged 13 to 93. We also reviewed other studies that asked women about their knowledge of bladder function and how they gained this knowledge.

Why did we do this study?

To summarize what the Prevention of Lower Urinary Tract Symptoms (PLUS) Consortium has learned so far about how women learn about bladder function (how the bladder works).

"I go yearly or more often, but **I don't remember a doctor ever discussing bladder health, what to do**. I don't recall ever having even discussed bladder."

What did we learn?

- Participants told us that there is not enough education in schools, medical offices, and public health programs in the US about what makes a bladder healthy and how to keep it healthy.
- Without this type of *formal* education, women learn about what is normal and what might not be normal from many *informal* sources. Informal sources include websites, TV, social media and people they know.
- Some examples of informal ways women learn about the bladder are:
  - *Talking* with others.
  - *Watching* those around them, for example noticing how many times people pee during the day and night.
  - *Figuring out* how to handle access to public toilets (for example, restricted access to bathrooms at school, work, home, commercial and public locations).
  - *Noticing* what is normal for their own bodies.
- There is frustration with the lack of reliable bladder health education.
- Gender minority persons may face even more challenges.

What was the overall conclusion?

We expect to learn more about women's knowledge from current PLUS research. This will help to develop:

- Educational content for health classes in schools.
- Educational content to provide women during specific life events such as puberty and pregnancy.
- Public health programming to improve bladder health throughout women's lives.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu

To learn more, please see the full article: Rickey LM, et al.; Women's Knowledge of Bladder Health: What We Have Learned in the Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. Curr Bladder Dysfunct Rep. 2022 Sep;17(3):188-195.
To read the full article:

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

What does bladder health mean to girls and women?

Purpose

In this study, we wanted to explore what girls and women think it means to have a "healthy bladder".

What We Did

We conducted focus groups with girls and women aged 11 to 93 at seven sites across the US. In small discussion groups with members of similar age, participants were asked to share their ideas about what it means to have a healthy or unhealthy bladder.

What We Learned

- In general, the idea of a healthy bladder seemed unfamiliar at first to most girls and women.
- Many girls and women described a healthy bladder as one that you don't have to think about.
- A healthy bladder was also described as having good control (being able to wait to go to the bathroom without worrying about having an accident or leaking) and not having to pee too often.
- Many girls and women wanted more information about what habits would help someone have a healthy bladder.

What's next

These results suggest there is a need for more education about bladder health, for example during health care visits.

For more information, please see the published article:
Low LK, et al. The many facets of perceived bladder health in women: Absence of symptoms and presence of healthy behaviors across the life course, Continence, Vol 13, 2025, 101726, ISSN 2772-9737.
https://www.sciencedirect.com/science/article/pii/S2772973724010014

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Study Results

Bladder Health Experiences and Opinions of Sexual and Gender Minorities (SHARE MORE)

Public Bathroom Experience of Persons of Sexual and Gender Minority Identities

PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Purpose of the Study

There is little information available on bladder health and lower urinary tract symptoms for sexual and gender minority communities. In this study, we wanted to learn more about the bladder health experiences of persons who identify their sexual orientation and gender differently than cisgender-heterosexual.

Who Participated?

In 6 focus groups, we heard from persons who identify their sexual or romantic attraction as queer, bisexual, lesbian, or gay, and who identify their gender as woman, gender queer or nonconforming, trans masculine, or another gender identity.

What did we learn?

- Gender specific bathrooms can be spaces where gender identity is affirmed- but for gender minority people, gender specific bathrooms can be much more complex and challenging.
- Early childhood experiences shaped participants' understanding of gender specific bladder health norms. For example, girls often socialize in bathrooms, while boys often do not even look at one another.
- Bathrooms designated male or female (men or women) can cause people who identify as queer or non-heterosexual to feel the need to hide their identity or alter their toileting behaviors to avoid feeling uncomfortable or threatened.
- Focus group participants described avoiding public bathrooms or leaving public bathrooms abruptly, leading to holding urine for long periods of time.
- Participants reported having anxiety and fear related to experience using the bathroom. The bathroom is for some people a place to seek privacy or quiet alone time, but for people of gender or sexual orientation minority identities, public bathrooms can be places where violence & harm might occur.

To learn more, see the research article:

Hardacker, C.T et al. Bladder Health Experiences, Perceptions and Knowledge of Sexual and Gender Minorities. Int. J. Environ. Res. Public Health 2019 , 16, 3170. Link to full article: 10.3390/ijerph16173170

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Study Results

Validation of Bladder Health Instrument for Evaluation in Women (VIEW)

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Research Article Summary:

Healthy Bladder Function: What we learned from a 2-day Bladder Health Diary.

Why?

To better understand what a healthy bladder should do, we gathered information from 237 women using a new bladder health diary.

What is a bladder health diary?

A bladder health diary collects information about toileting habits like when and how often a person pees.

What did we do?

As part of the VIEW study (Validation of Bladder Health Instrument for Evaluation in Women) we asked women to record information every time they peed for 2 days. Then we analyzed the data from 237 completed diaries.

Who did we ask?

We invited 383 women who participated in the VIEW study to complete bladder diaries. Of those invited, 237 women completed the diaries. Women in the VIEW study were age 18 years and older, identified as a female or woman, living in communities (not nursing homes or other institutional settings).

What does “healthy bladder function” mean?

Healthy bladder function was measured in 2 parts:

- Being able to keep or store pee in the bladder
- Emptying (peeing) comfortably and fully
- Each part was measured by several questions in the diary

Key findings:

- Only 12% of women in the study had overall healthy bladder function.
- Most women reported one or more “unhealthy” bladder function experiences, such as leaking urine after peeing (“Post-void dribbling”).
- This was the most common unhealthy function, followed by feeling like one needs to pee right away (“sensation of urgency to pee”).
- 3 of 4 women peed 8 or fewer times during daytime and 1 or fewer times at night. Peeing more than that might be a sign of bladder problems.
- One out of three women leaked urine. Most of these women reported only mild leakage.
- Pain related to bladder function was very rare.

What is next?

Future research should focus on whether or not women view these changes in bladder storage and emptying functions as unhealthy, to reach a more complete definition of bladder health and more precise clinical treatment goals.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu

The complete article by ES Lukacz et al. 2023 “Healthy Bladder Storage and Emptying functions in community-dwelling women measured by a 2-day bladder health Diary CLS” can be found in *Neurourol Urodyn.*
To read the full article: https://doi.org/10.1002/nau.25169

Study Results

RISE FOR HEALTH

Introducing the RISE FOR HEALTH Study

WHAT IS THE PURPOSE OF THE ARTICLE?

This paper explains the RISE for HEALTH study of women's bladder health throughout their lives. The study will collect information about the health of bladders in women from all over the United States.

Why is RISE FOR HEALTH being done and why is it important?

We don't know enough about women's bladder health across the U.S., which led to the development of RISE for HEALTH.

How are we doing the research?

At the beginning of the study, we will ask participants to fill out two surveys about the health of women's bladders. Some participants will have one in-person clinic visit where they will have a physical assessment and provide lab samples. One year later, we will send those who took the first two surveys a third one to see how things have changed.

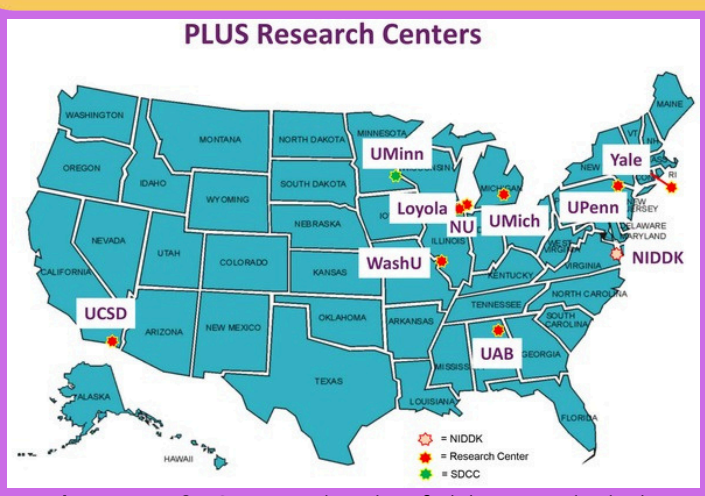
How many participants are expected to participate?

For the baseline survey the goal is for **4750** participants to participate and **525** participants for the in-person visit.

Continue to Back Page

Where is the research taking place?

RISE for HEALTH will invite women from the 50 counties surrounding the 9 clinical research centers of the PLUS consortium.



The clinical research centers of RISE are: University of Alabama at Birmingham, University of California San Diego, Emory University, Loyola University Chicago, University of Michigan, Northwestern University, University of Pennsylvania, Washington University St. Louis, and Yale University.

Conclusion

By including a diverse population from U.S. regions and across the life course, RISE will provide rich information and a fuller understanding of bladder health in women. These findings will aid in building future bladder health promotion programs.

To learn more, please see the research article:

https://onlinelibrary.wiley.com/doi/10.1002/nau.25074
Smith AL, et al. 2022. Introducing RISE FOR HEALTH: Purpose, Study Design, Expected Results. Neurourology and urodynamics.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Engaging Communities in Design of Research Materials for the RISE FOR HEALTH Study

RISE FOR HEALTH

Purpose of the Article:

This article shares the methods used by the PLUS Consortium to engage community members in the design of RISE FOR HEALTH study materials. It describes a community engagement model that can produce more inclusive recruitment materials and surveys.

What does "engagement" mean?

For the RISE study, research staff invited community members to participate in groups that were called Rapid Assessment Partners (RAPs) to review materials such as study invitation letters, surveys, and the RISE website. The specific methods of engagement are shown in the box to the right. ------>

Who participated?

Community members were invited by six RISE research centers across the U.S. to review materials.
In addition to geographic diversity, community members included women 18 years of age and over, who represented several dimensions of diversity such as age, race, gender identity (except for cisgender men), and Latina/x ethnic identity.

Community Member Engagement Activities

- Research staff asked RAP members to look carefully through materials such as invitation letters, survey questions, the RISE website, and to provide feedback about them. Feedback was provided in surveys, virtual discussion groups, and/or one-on-one interviews.
- 14 virtual discussion groups were conducted in all. During one-hour virtual sessions, RAP members shared more in-depth thoughts about the research materials.
- 12 one-on one interviews were conducted with community members when the content was sensitive, such as questions about planned clinical procedures to assess bladder health.

Examples of specific changes made as a result of community input:

1. The study's name was selected: RISE FOR HEALTH

2. Improvements were made in the language and design of recruitment/invitation materials based on comments by RAP members

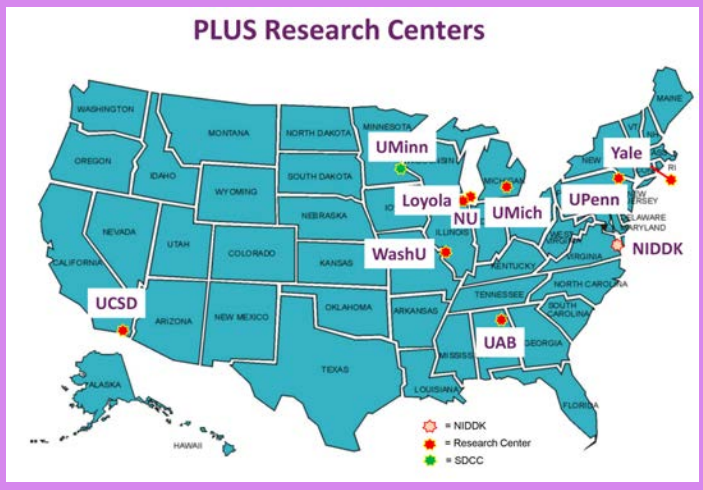
3. Language of survey questions was made more clear and inclusive

4. Study procedures were changed for the in-person clinic visit, based on what RAP members said

Main Outcome:

The research activities described in this article (details below) demonstrate that engaging community partners in the research process at an early stage, even if not from the very beginning, can be fruitful and improve the quality of research.

To learn more, please see the research article: Heather Klusaritz, Julia Maki, Elise Levin, Amy Ayala, Jesse Nodora, Tamera Coyne-Beasley, Jeni Hebert-Beirne, Terri H. Lipman, Aimee James, Emily Gus, Shayna D. Cunningham, Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. A community-engaged approach to the design of a population-based prospective cohort study to promote bladder health. Neurourol Urodyn. 2023; 42: 1068-1078. doi:10.1002/nau.25098



The PLUS Consortium is a group of research centers that convened initially in 2015 to conduct research on women's bladder health in the U.S. PLUS stands for the Prevention of Lower Urinary Tract Symptoms.
The clinical research centers of RISE are: University of Alabama at Birmingham, University of California San Diego, Emory University, Loyola University Chicago, University of Michigan, Northwestern University, University of Pennsylvania, Washington University St. Louis, and Yale University.
University of Illinois Chicago and University of Minnesota are also a part of PLUS and RISE FOR HEALTH.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

The RISE FOR HEALTH Study: Understanding the range of bladder health in American women

Purpose

In this study, we wanted to understand the range of overall bladder health in women from across the US.

What we did

We surveyed women as part of the RISE FOR HEALTH study. 3,027 women answered questions about:

- how well they feel their bladder works,
- any bladder problems they have, and
- any ways they manage bladder problems.

Bringing all the questions together, we came up with a single score, which ranged from **0, the worst possible bladder health**, to **100, the best possible bladder health.**

What we learned

- There was a wide range of bladder health scores, between 34 and 78.
- About 7 out of every 10 women (69%) said they use products or plan their behavior to manage their bladder. These women reported using pads, always knowing where the restrooms are located when away from home, and staying close to restrooms.
- Bladder health scores were better in women who didn't have bladder problems like leaking or pain. But, even in women without any problems, bladder health had a wide range and could still be improved.

What's next?

These results show us that there is a lot of room for improvement in women's bladder health. Our way of measuring and scoring bladder health may help find groups of women who are more likely to have bladder problems in the future.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

FOR MORE DETAILS, SEE THE ORIGINAL PAPER:
SMITH AL, ET AL. BLADDER HEALTH IN US WOMEN: POPULATION-BASED ESTIMATES FROM THE RISE FOR HEALTH STUDY. AM J OBSTET GYNECOL. 2024 NOV 7:S0002-9378(24)01116-5. DOI: 10.1016/J.AJOG.2024.10.044. EPUB AHEAD OF PRINT. PMID: 39521302. HTTPS://PUBMED.NCBI.NLM.NIH.GOV/39521302/

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Bladder Symptoms in US Women: Results from the RISE FOR HEALTH Study

Why did we do this study?

We wanted to understand how common bladder symptoms are in US adult women.

What did we do?

We asked 3,000 women how often they experience bladder symptoms like a sudden need to pee, leaking, feeling like they have pee left in their bladder after peeing, and pain or discomfort. We also asked how much these symptoms bothered them and whether they have talked to anyone about them.

WHAT DID WE LEARN?

- **About 4 out of 5 women (79%) told us they have had these kinds of symptoms in the last 7 days.**
- **More than 1 in 3 (38%) told us they were at least somewhat bothered by the symptoms.**
- **Only about 1 in 3 (38%) had talked to anyone about their symptoms.**

These findings suggest that programs to treat and prevent bladder problems are badly needed. Although many researchers and women have seen this need for a long time, these results give us important data supporting future action for women across the US.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

FOR MORE DETAILS, SEE THE ORIGINAL PAPER:
SUTCLIFFE S., ET AL, LOWER URINARY TRACT SYMPTOMS IN US WOMEN: CONTEMPORARY PREVALENCE ESTIMATES FROM THE RISE FOR HEALTH STUDY. J UROL. 2024 JUL;212(1):124-135.
HTTPS://WWW.AUAJOURNALS.ORG/DOI/EPDF/10.1097/JU.0000000000004009

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Genital pain and bladder symptoms in the RISE for HEALTH Study

Purpose

We wanted to understand how bladder symptoms and genital pain are related in women.

What We Did

1,973 women who completed the RISE for Health survey told us about their experiences with bladder symptoms and genital pain. Bladder symptoms include things like a sudden need to pee, leaking pee, feeling like you still have pee in your bladder after peeing, and pain or discomfort when peeing. Genital pain includes feeling burning or other pain in the genital area, except because of a urinary tract infection.

WHAT WE LEARNED

- **About 13% of women who took the survey told us they had genital pain during the last 7 days.**
- **Women with genital pain were more likely to also have bladder health symptoms than women without pain.**
- **Although we don't yet understand how these conditions affect or potentially cause each other, it suggests that clinicians who treat women with genital pain should ask them about bladder symptoms as well.**

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

FOR MORE DETAILS, SEE THE ORIGINAL PAPER:

Harlow, BL., et al. "Genital Pain and the Spectrum of Bladder-Related Symptoms: Findings from the Prevention of Lower Urinary Tract Symptoms Research Consortium RISE FOR HEALTH Study, USA." International Urogynecology Journal (2024): 1-11.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Exploring Women's Bladder Self-Care Practices

Purpose

We wanted to better understand how women care for their bladder, including what they do to prevent or manage bladder symptoms.

What We Did

We explored data from the SHARE (Study of Habits, Attitudes, Realities, and Experiences) focus groups. These focus groups included 316 women, aged 18 to 93 years. Women shared ways they care for their bladder using clothing, bathing, food and drinks, exercise, medicines, sexual practices, and how and when they use the toilet.

What We Learned

Women described using a wide range of approaches and activities to address bladder health:

- Careful thought about when and what fluids to drink
- Prescription, over the counter, or home remedies for bladder symptoms
- Easy to remove clothing
- Having extra clothing in case of leaks
- Careful bathing and wiping
- Avoiding public restrooms
- Peeing after sex
- Practicing pelvic floor exercises (Kegels)
- Changing exercise habits
- Making sure they know where all the restrooms are when away from home

More research is needed to understand which of these methods are best for bladder health, and to make sure none of the methods make health worse. Programs can use this information to teach girls and women about ways to care for their bladder.

For more information, please see the published article:
Wyman JF, et al.; Exploring women's bladder self-care practices: A qualitative secondary analysis. J Adv Nurs. 2024 Jun 12. https://doi.org/10.1111/jan.16257

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Is there a relationship between financial strain and bladder health in women?

Purpose

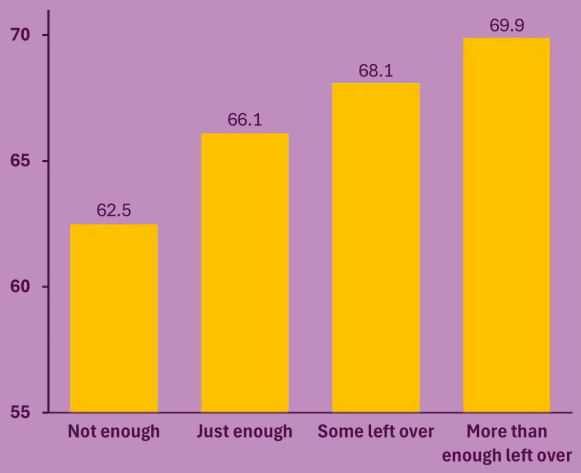
Financial strain means not having enough money to meet basic needs, like stable housing, healthy food, and reliable transportation. We wanted to understand whether financial strain is related to worse bladder health.

What We Did

We asked women aged 18 and older from around the United States about their bladder health and their experiences with different types of financial strain.

What We Learned

We found that women who had experienced financial strain were more likely to have worse bladder health. On average, the more financial strain women reported (or the less money they had to pay for basic needs), the worse they described their bladder health.



This chart shows women's self-rated bladder health, where 0 is the worst and 100 is the best. The yellow bars show the average bladder health score based on how much money women said they have left over at the end of the month. On average, self-rated bladder health is better as women have more money left over at the end of each month.

To learn more, please see the published article:
Wyman JF, Zhou J, Yvette LaCoursiere D, Markland AD, Mueller ER, Simon L, Stapleton A, Stoll CRT, Chu H, Sutcliffe S. Normative noninvasive bladder function measurements in healthy women: A systematic review and meta-analysis. Neurourol Urodyn. 2020 Feb;39(2):507-522. doi: 10.1002/nau.24265. Epub 2020 Jan 9.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Are urine samples collected at home similar to samples collected in a clinic?

Purpose

Researchers believe that the bacteria and other microbes found in normal, healthy urine (pee) may be important to understanding bladder health. To study this, researchers have always needed women to come to a doctor's office or hospital to provide a pee sample. This makes it hard to study urine samples from women in a wide variety of communities and places that are far from the clinic.

In this study, we wanted to learn whether pee samples collected at home have important differences in bacteria from samples collected in a doctor's office or hospital.

What We Did

114 women participating in the RISE FOR HEALTH STUDY gave 186 samples of pee. Samples were collected at home two days in a row, then again at a doctor's office or hospital the same day. The types of bacteria from these three samples were compared.

What We Learned

We found that samples from the same woman were generally similar between days and between the home and the doctor's office or hospital.

What's next

This study shows that researchers who want to study bacteria and microbes can use samples of pee collected at home, so women do not have to travel to a clinic. It is important to point out that urine samples needed for medical reasons, like figuring out if a patient has a urinary tract infection (UTI) still need to be collected in a doctor's office.

For more information, please see the published article:
Lukacz, Emily, Fok, Cynthia, MD, MPH, Bryant, MacKenzie, Rodriguez-Ponciano, Dulce, Meister, Melanie, PhD, MPH. (2024). Feasibility of Home Collection for Urogenital Microbiome Samples. Urogynecology, 30, 896-905.
https://journals.lww.com/fpmrs/fulltext/9900/concordance_of_urogenital_microbiome_from.303.as

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Is there a relationship between bladder health and social determinants of health?

PURPOSE

Social determinants of health (SDoH) are the conditions where people are born, grow, learn, work, play, live, and age that shape health.

Research has shown that ethnic and racial minority groups tend to experience SDoH that place them at risk for poor health.

We looked at whether ethnic and racial identity were related to women's bladder health, and whether SDoH might explain this relationship for some women.

What We Did

As part of the RISE FOR HEALTH Study, we asked women aged 18 and above from 9 regions in the United States to answer questions about their bladder health, ethnic and racial social identity, and SDoH.

What We Learned

- Hispanic women had worse bladder health in comparison to Non-Hispanic White women. This appeared to be explained by SDoH, specifically reported lower levels of education, higher levels of poverty, and no insurance or limited insurance.
- Non-Hispanic Black and White women reported similar levels of bladder problems. However, Black women felt their bladder health was better compared with White women.
- Non-Hispanic Asian women reported fewer bladder problems and better bladder health compared to Non-Hispanic White women. These differences were not explained by SDoH.

What's Next?

Programs and policies to improve bladder health must address differences women experience in education, finances, and medical care coverage and quality. This may be especially important for Hispanic women where SDoH are less likely to support bladder health.

For more details, see the original paper:
Brady SS, et al. Ethnic and Racial Social Identity, Socioeconomic Position, and Women's Bladder Health, Social Science & Medicine, 2025,117694, SSN 0277-9536 https://www.sciencedirect.com/science/article/pii/S0277953625000231

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

IS THERE A RELATIONSHIP BETWEEN WHEN AND HOW WOMEN USE THE TOILET AND BLADDER HEALTH?

PURPOSE

We wanted to understand whether there is a relationship between bladder health and the ways that women use the toilet. For example, whether they hold or wait too long to pee, pee before they feel the urge, strain when peeing, or pee using certain types of positions.

WHAT WE DID

2,327 women between the ages of 18 and 101 participated in the national RISE FOR HEALTH survey. They told us about their bladder health, when they pee and the ways that they prefer to use the toilet.

WHAT WE LEARNED

- Women who told us they avoid toilets when away from home, hold or wait too long to pee, pee before they feel the urge, or strain to pee also reported more and worse bladder symptoms.
- Waiting too long to pee and peeing before feeling the urge to go were most strongly linked with symptoms like having a sudden need to pee, leaking, and pain.
- Waiting too long to pee was linked to bladder symptoms in women of all ages. But this link was strongest in women between 18 and 25 years old.

WHAT'S NEXT?

This study suggests that women's bladder health may be related to the ways they use the toilet. More studies are needed to learn if these behaviors cause or worsen existing bladder problems, if existing bladder problems cause women to change behaviors to address symptoms, or both.

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine US universities. Learn more at www.plusconsortium.umn.edu.

To learn more, see the article:

Berry, Amanda, et al. "Associations Between US Women's Toileting Behaviors and Lower Urinary Tract Symptoms: A Cross-Sectional Analysis of RISE for HEALTH Study Data." J Womens Health (Larchmt). 2025 Mar 3.

plus
PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

Bladder Health, Menopause and Hormone Use in Women in the RISE FOR HEALTH Study

Purpose

We wanted to understand if there is a relationship between hormone use and bladder health in women during and after menopause.

What We Did

We surveyed women aged 18 years and older from around the US as part of the RISE FOR HEALTH Study. 3,126 women told us about their menopausal status, whether they use any hormone medications (for example, vaginal estrogen, birth control or hormone pills, hormone patch, vaginal estrogen ring, or hormonal IUD), and their bladder health, including any bladder problems they might have. Bladder problems included things like urine leaking, bladder pain, or a sudden need to pee.

What We Learned

- Women who had begun or had already gone through menopause were around 2 times more likely to have bladder problems compared with women who hadn't yet started menopause.
- In women who had begun or had already gone through menopause, women who were taking hormone medications were more likely to have bladder problems than women who were not taking hormone medications.

What's Next?

- **This study can't say for sure if hormone medications cause bladder problems. Future studies will be needed to see if taking hormone medications contributes to increased bladder problems in women around menopause.**
- **In the meantime, healthcare providers should be sure to talk to women who are beginning or have gone through menopause about potential bladder problems, especially if they use hormone medications.**

For more information, please see the published article:
XXXXXXXXXXXXXXX

PLUS Consortium research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health and includes researchers from nine American universities. Learn more at www.plusconsortium.umn.edu.

Thank you for learning about women's bladder health!

The following people contributed to the creation of these research summaries:

Katelyn Adams
Amy Ayala
Teresa Berumen
Julia Blount
Jaelyn Brown
Hannah Burns
Shayna Cunningham
Fentyshia Daniels
Linda Delgado
Divya Goel
Kyle Herrala
Glenda James
Rosella Lencioni
Elise Levin
Julia Maki
Saundi McClain-Kloeckener
Jesse Nodora
Jenna Norton
Katlin Nucsis
Hilary Opperman
Ratna Pakpahan
Sara Putnam
Kym Radford
Leslie Torrijos
Ava Wells-Quantrell
Selena Williams Earley
Rachel Yoken

plus PREVENTION OF LOWER URINARY TRACT SYMPTOMS
A Research Consortium of the National Institutes of Health

For more information about PLUS and bladder health please visit: **www.plusconsortium.umn.edu**