# Health Ministers: Destigmatizing Bladder Health Through Community Education

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## INTRODUCTION

**LUTS have significant public health consequences.** Lower Urinary Tract Symptoms (LUTS)—such as urinary incontinence, frequency, urgency, and nocturia—are common, especially in older adults. Estimates suggest more than 30 million Americans experienced LUTS in 2000. [1]By 2025, with aging of the U.S. population, prevalence of LUTS is expected to grow to more than 42 million. [1]Individuals who experience LUTS report similarly low quality of life scores to diabetes, hypertension, cancer, and—in severe cases—heart attack and stroke. In addition to reducing quality of life, LUTS may have important public health consequences. Individuals who experience LUTS are less likely than individuals with normal bladder function to achieve recommended levels of physical activity,[2] which may exacerbate risk for obesity and obesity related conditions. Particularly in elderly populations, nocturia and urgency may increase risk for falls and fractures,[3,4] as individuals rush to the bathroom. Additionally, LUTS may increase social isolation.[5]

### Prevalence of LUTS in Men and Women, 2000 versus 2025

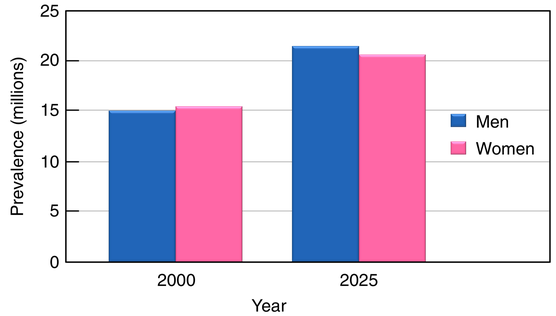



*Image developed based on data from Litman, et al. 2007[1]*

**LUTS are costly.** Data on the total cost of LUTS are limited, but the economic impact of individual LUTS-associated conditions is significant. For example, direct costs related to healthcare treatment for urgency urinary incontinence are estimated to be $76.2 billion in 2015 and $82.6 billion in 2020.[6] Importantly, these estimates do not include self-care costs (e.g., use of pads or diapers) for the many women who do not seek care.

### Estimated Direct Costs for Urge Urinary Incontinence Care, 2015 and 2020

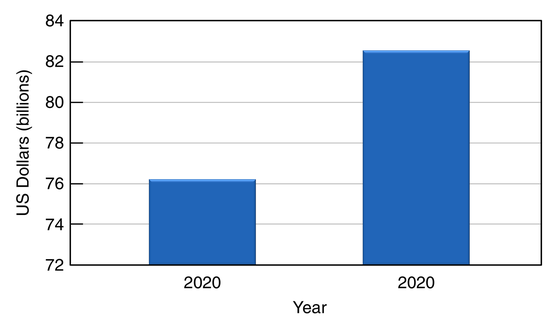
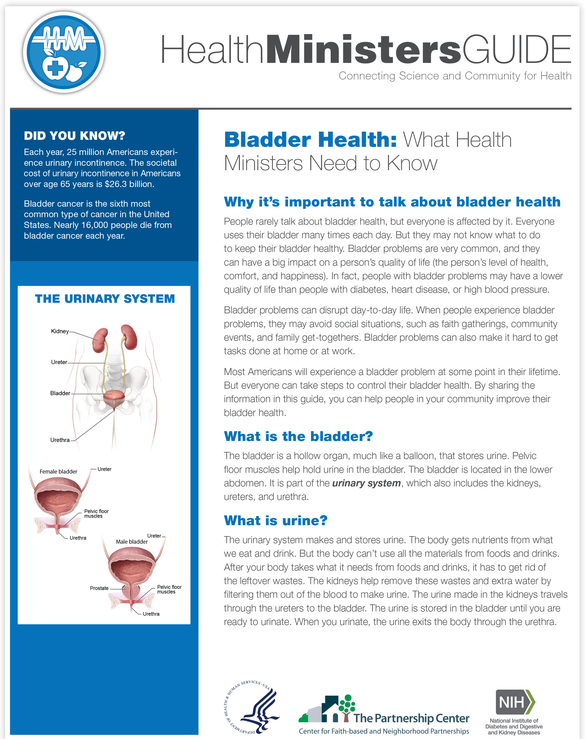



*Image developed based on data from Coyne, et al. 2014[6]*

**LUTS are stigmatized.** Despite the prevalence of LUTS, many individuals who experience LUTS report embarrassment and shame around their symptoms.[7,8,9] Embarrassment has been identified as a barrier to seeking medical attention for LUTS. Lack of care seeking prevents appropriate care and hinders identification of patients needed for research to better understand secondary prevention and treatment strategies.

**Health ministers can play a critical role in bladder education.** Increased bladder health knowledge may reduce stigma and encourage care seeking, but sociocultural barriers and medical mistrust impede education at the community level. These barriers can challenge institution-based public health communication, including education efforts from medical systems and federal or local governments. However, community-level, interpersonal networks may represent a key opportunity for overcoming these barriers. Advice from within an informal, interpersonal network (e.g., friends, family, community members) can have a significant impact on health decision-making.[11,12,13] As such, community-level influencers represent a unique and important opportunity for effectively delivering public health messages that promote positive health behavior change. As cultural key holders, ***health ministers*** have access and influence to overcome barriers, guide provision of culturally competent care, and adjust stigmatizing social norms around bladder issues. Health ministers have deep knowledge of their communities and when appropriately trained, are able to provide early intervention.

**The Health Minister Guide series provides information to help health ministers lead community education.** The Department of Health and Human Services' Center for Faith-based and Neighborhood Partnerships (HHS Partnership Center) is developing a Health Minister Guide series on numerous topics to support health ministers in community health outreach. The guides aim to prepare health ministers to educate and activate their community. Each Health Minister Guide is being developed in concert with health ministers and the topic-appropriate Federal science agency or institution to ensure guides provide accessible, evidence-based information. The inaugural Health Minister Guide, *Bladder Health: What Health Ministers Need to Know*, aims to raise awareness of bladder health and provide information to help health ministers educate their communities. This poster describes development and formative evaluation of the bladder health guide.


HealthMinistersGUIDE
Connecting Science and Community for Health

**DID YOU KNOW?**
Each year, 25 million Americans experience urinary incontinence. The societal cost of urinary incontinence in Americans over age 65 years is $26.3 billion.

Bladder cancer is the sixth most common type of cancer in the United States. Nearly 16,000 people die from bladder cancer each year.

**THE URINARY SYSTEM**

Kidney
Ureter
Bladder
Urethra
Female bladder
Ureter
Pelvic floor muscles
Urethra
Ureter
Male bladder
Prostate
Pelvic floor muscles
Urethra

**Bladder Health:** What Health Ministers Need to Know

**Why it's important to talk about bladder health**

People rarely talk about bladder health, but everyone is affected by it. Everyone uses their bladder many times each day. But they may not know what to do to keep their bladder healthy. Bladder problems are very common, and they can have a big impact on a person's quality of life (the person's level of health, comfort, and happiness). In fact, people with bladder problems may have a lower quality of life than people with diabetes, heart disease, or high blood pressure.

Bladder problems can disrupt day-to-day life. When people experience bladder problems, they may avoid social situations, such as faith gatherings, community events, and family get-togethers. Bladder problems can also make it hard to get tasks done at home or at work.

Most Americans will experience a bladder problem at some point in their lifetime. But everyone can take steps to control their bladder health. By sharing the information in this guide, you can help people in your community improve their bladder health.

**What is the bladder?**

The bladder is a hollow organ, much like a balloon, that stores urine. Pelvic floor muscles help hold urine in the bladder. The bladder is located in the lower abdomen. It is part of the ***urinary system***, which also includes the kidneys, ureters, and urethra.

**What is urine?**

The urinary system makes and stores urine. The body gets nutrients from what we eat and drink. But the body can't use all the materials from foods and drinks. After your body takes what it needs from foods and drinks, it has to get rid of the leftover wastes. The kidneys help remove these wastes and extra water by filtering them out of the blood to make urine. The urine made in the kidneys travels through the ureters to the bladder. The urine is stored in the bladder until you are ready to urinate. When you urinate, the urine exits the body through the urethra.

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## METHODS

**Content Development.** The HHS Partnership Center worked with the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) to develop content for *Bladder Health: What Health Ministers Need to Know*. Content was developed by a public health professional with communication experience, a social worker, and a urologist with more than 20 years of clinical experience. Content was guided by peer-reviewed published literature and was reviewed for accuracy by NIDDK clinicians and scientists. Early drafts of the guide were also reviewed by health ministers and faith leaders who work actively within their community to ensure messages and language were audience appropriate.

**Focus Group Testing.** The HHS Partnership Center partnered with the Wesley Theological Seminary to conduct focus groups to acquire health minister feedback on an initial draft of the guide. Three, one-hour focus groups were arranged with health ministers from a variety of backgrounds (**TABLE 1**). A discussion guide was developed to ensure feedback was solicited on a variety of topics, including overall reaction to the guide, usefulness/efficacy of the guide, appropriateness of language and design, unnecessary/unhelpful content, missing content that would be helpful, and general suggestions for improvement. Focus group discussion was recorded to ensure accurate capture of feedback. Feedback was reviewed and themes from across focus group responses were identified.

### TABLE 1: Focus Group Descriptions

| Location | Number of Participants | Description of Participants |
|---|---|---|
| Pennsylvania Avenue Baptist Church, Washington, DC | 18 | Participants were identified from the Wesley Theological Seminary's Faith Community Health Networks (FCN). The focus group was held in conjunction with an FCN meeting to facilitate attendance. Participants included faith leaders of multiple faiths, including Christianity and Islam, from Wards 7 & 8 of Washington, DC. Participants were a mix of lay health ministers and nurses actively involved in health ministry. |
| District of Columbia Department of Health, Washington, DC | 6 | Participants were identified from the DC Department of Health's Places of Worship Advisory Board (POWAB). The focus group was held in conjunction with a POWAB meeting to facilitate attendance. Participants included faith leaders from two DC area faith communities and one Community Health Specialist from the DC Department of Health. |
| Trinity United Methodist Church, Frederick, MD | 8 | Participants were identified from the Wesley Theological Seminary's FCN. The focus group was held in conjunction with an FCN meeting to facilitate attendance. Participants included faith leaders from western Maryland, southern Pennsylvania, and the Washington Metropolitan. Participants were primarily nurses involved in health ministry and included one health advocate hospital coordinator. |

## RESULTS

Several key themes emerged from the focus group testing:

- **Overall feedback on the guide was highly positive.** Most participants felt the guide increased their knowledge and understanding of bladder health. Several participants reported increased interest in promoting bladder health among their communities after reviewing the guide.
- **The meaning of the term "health minister" varies widely across groups.** Some participants perceived the term as being associated with Christianity and exclusive of people who were not of Christian faith. Many participants felt "health minister" referred to someone with specific ministerial training or education, while others felt the term could be applied broadly to any individual interested in "ministering" to their communities. The draft of the guide tested in focus groups included a secular definition of a health minister. Several participants who felt the term had strong and specific faith associations were uncomfortable with this definition.
- **Accompanying materials are needed to support health minister-led community education.** Most participants felt accompanying materials with messages directly targeting community members would be necessary to enable health minister-led education. Specifically, participants suggested the urinary tract diagram and urine color chart included as images in the guide should be provided as a separate handout. Additionally, participants recommended development of materials such as interfaith prayers for healing, articles for posting in faith community bulletins, meeting planning tools, video clips, and slide sets for group education classes.
- **Stigma is an important issue that must be addressed in order to discuss bladder health.** Several participants noted the importance of overcoming stigma when providing education on bladder health. Participants recognized they are in a position to address stigma, expressed enthusiasm about contributing to stigma-reduction efforts, and suggested providing information and resources to address stigma in the guide.
- **Individual communities need to understand why bladder health is important to their specific community.** Participants highlighted the need to understand how bladder health is relevant to their specific community. Participants suggested individualized community-level statistics or relevant testimonials may demonstrate relevance to a community.

Additionally, several minor word revisions (e.g., "hydrated" vs "drinking enough fluid") and design changes (e.g., color contrast between text and background) were suggested to improve literacy and legibility.

## DISCUSSION

**Addressing focus group feedback.** Both content and design revisions were made to the guide based on focus group feedback. Revisions were reviewed by a urologist from the NIDDK to ensure content remained scientifically accurate. Key changes included:

- Removal of the "health minister" definition from the guide. Removal of the definition allows each user to assume his or her own definition of "health minister."
- Addition of links to community facing materials covering bladder health topics.
- Addition of content about the stigma surrounding bladder health and strategies for addressing shame or embarrassment about LUTS in community members.

Additionally, the HHS Partnership Center is exploring development of specific complementary materials to accompany the guide. These materials would be designed to help health ministers provide bladder health information directly to community members. Also, the Partnership Center hopes to work with communities to develop community-specific testimonials and statistics that will help engage health ministers and community members from those communities.

**Launching the guide.** The HHS Partnership Center will launch the guide during Bladder Health Week—November 8 -14, 2015. The launch will include blog posts to promote the guide, as well as an interactive webinar with health ministers to discuss the importance of bladder health. The webinar will feature presentations from a health leader, urologist, and person with LUTS.

## ACKNOWLEDGEMENTS

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