



## PATIENT GUIDE

# Presenting the Clinician Resource, *Improving Treatment Pathways for Patients with Persistent Lower Urinary Tract Symptoms*

### PURPOSE:

This patient guide and worksheet was developed to assist you and other patients with persistent UTIs to more effectively communicate with and present recent research to your clinicians. Included are tips for preparing for your appointment and presenting the accompanying resource to your clinician.

We understand that as someone with a persistent urinary tract infection (UTI), it can be difficult to achieve effective communication between you and your provider, regardless of the research you may have done on the topic. The combination of complicated medical journal terminology and a clinician's limited time with patients often impedes a productive exchange of information.

The clinician's resource has been created as a tool to help bridge these gaps in information exchange between you and your provider regarding UTI diagnostics. The resource covers some of the fundamental topics surrounding persistent or difficult to diagnose UTI, supported by peer-reviewed articles.

The topics are presented in an easy-to-navigate format with in-document links. This means, when presented to your clinician in a digital format, they can skip directly to sections of interest without wading through excess information. If you prefer, you may also print this resource to hand to your provider at your next appointment.

We recommend that you review and familiarize yourself with the overview for each of these topics (listed below) to prepare for your next appointment. At the end of this guide, we have also included a worksheet to help you prepare for your appointment.

With your provider's permission, present to them the peer-reviewed research document, *Improving Treatment Pathways for Patients with Persistent Lower Urinary Tract Symptoms* during your appointment or in a digital format using this link.

***This guide has been created for patient use and is not necessary to present to your clinician.***

## TOPICS INCLUDED IN THE CLINICIAN RESOURCE

- The bladder microbiome (urobiome)
- Limitations of standard urine culture (SUC)
- Alternative diagnostic methods, including DNA testing
- The issue with 'contamination' or 'mixed-growth' urine culture reports
- Poor treatment outcomes due to unreliable diagnostics
- Alternatives to antimicrobial resistance testing
- Symptom overlap between UTI and symptom-based diagnoses, i.e. interstitial cystitis, overactive bladder, urinary incontinence
- How biofilm and intracellular bacterial communities contribute to persistent infection

## TIPS FOR PREPARING FOR YOUR APPOINTMENT

- **Review** and familiarize yourself with the information included in this document prior to presenting it to your clinician.
- **Consider goals** you'd like to accomplish during the appointment. Goals will be individualized depending on the patient-clinician relationship. Examples may include:
  - Clinician agreement to review the resource document
  - Clinician acknowledgement of limitations of SUC and agreement to explore further diagnostics
  - Clinician agreement to treat infection according to microscopy, advanced diagnostics, or symptoms
  - Clinician agreement to order imaging to rule out/in a structural component to lower urinary tract symptoms
- **Write down your history, and include the following:**
  - Timeline of symptoms
  - Previous treatments
  - Previous diagnostic tests
  - Review past SUC reports to determine if 'contamination' or 'mixed growth' were ever reported. If your clinician is open to reviewing the resource guide, your previous SUC reports may support the exploration of different diagnostic and treatment avenues.
- **Gather previous imaging and reports** to physically present to your clinician (if you have any). You should be able to access these through your online patient portal or by requesting them directly from your healthcare team.
- **Ask your clinician** how they would like you to relay your information, i.e., chronologically, a complete list of symptoms, etc. and try to stick to their preference.

- **Write a list of questions** you'd like to ask, such as:
  - How reliable are standard urine cultures?
  - What action do you take when a standard culture is negative, but a patient still has symptoms of a UTI?
  - Do you have any experience diagnosing and successfully treating persistent UTI? If so, what is your typical approach?
  - Do you have any experience with DNA-based testing methods for UTI such as PCR or NGS?
  - Are you aware of the possibility of biofilms being involved in persistent UTI? If so, how do you approach this problem?
- **Your clinician's response** to the above questions or your own unique questions can help determine if this clinician is the best fit for you and your goals.
- **When presenting** research-based information to your clinician, the information is likely to be better received by clinicians who have an established relationship with you, as opposed to you being a new patient. Consider this and the above recommendations when preparing for your appointment.

## TIPS FOR PRESENTING THIS RESOURCE TO YOUR CLINICIAN

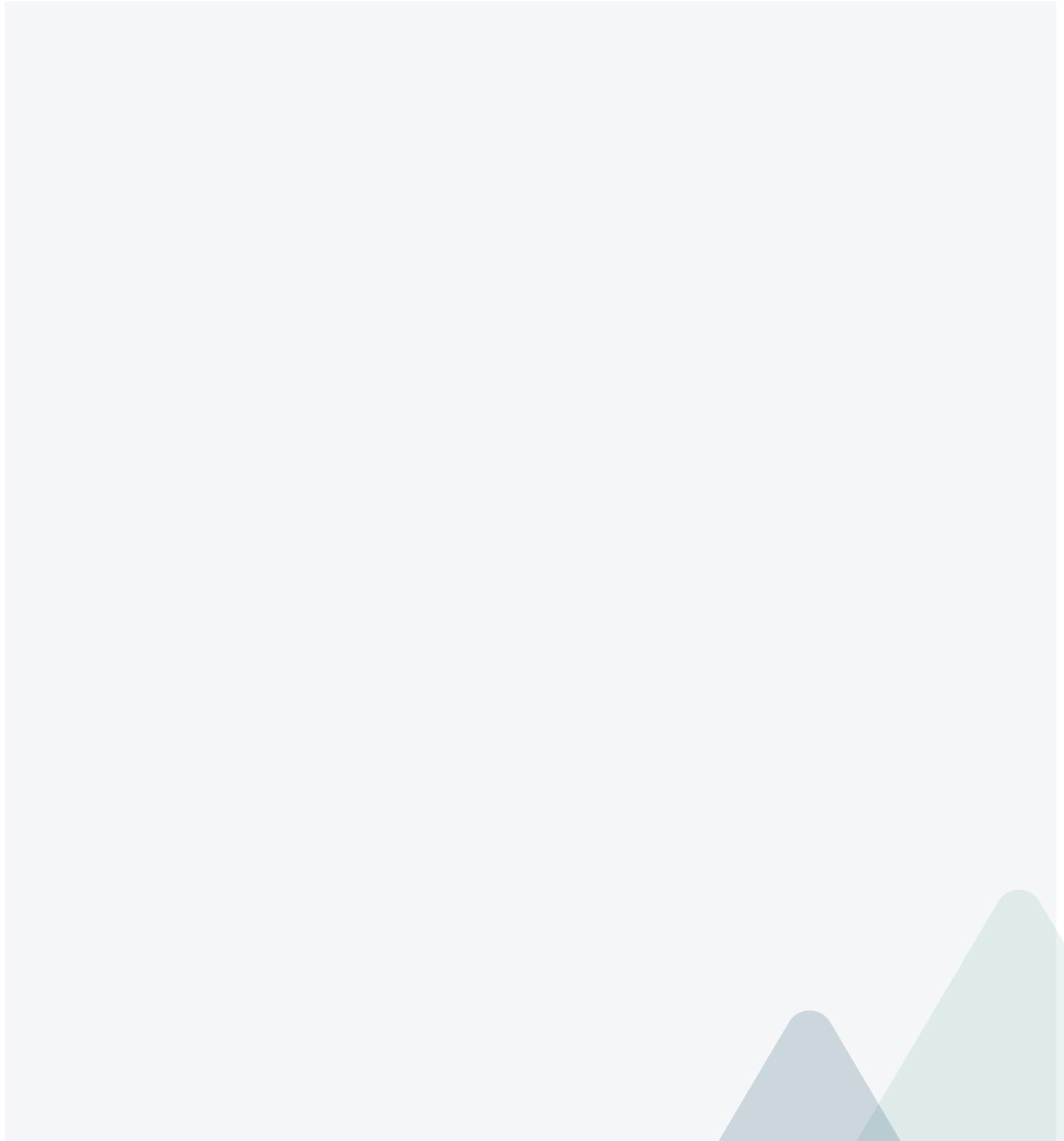
- **Thank** your clinician for the care they have provided to date (if applicable), and inform them that you are taking an active role in your healthcare decisions and would like to work with them collaboratively to achieve a desired outcome. Ask if they're willing to work with you in this capacity.
- **Adjust your mindset** to view yourself as a client hiring a clinician. If your clinician does not align with your goals and values, you can choose to hire a different clinician. When making this decision, consider the challenges that may come with finding a new clinician and weigh them against the benefits.
- **Remember** that you are your biggest health advocate. However, if you need an extra advocate during your appointment, ask a friend or family member to join you for additional support.
- **Inform** the clinician that you are affiliated with a patient education organization, and that they have shared peer-reviewed papers on the topic of lower urinary tract symptoms.
- **Request** your provider's permission to share these papers with them, as they may be related to your care.
- **Offer** the option of allowing your clinician time to review the documents prior to your next appointment and discussing further at that time.
- **After your appointment**, research tests and treatments that have been presented to determine if they align with your goals.
- **If you're not satisfied** with the outcome of the appointment or feel dismissed, be ready to move on and seek care from a clinician willing to pursue your goals with you.

## APPOINTMENT PREPARATION GUIDE AND WORKSHEET

Prior to your appointment, you may complete and use this form as a guide to help you stay organized and keep the conversation focused.

**Consider goals** you'd like to accomplish during the appointment. Goals will be individualized depending on the patient-clinician relationship. See examples from the previous section or create your own goals.

**My goals for this appointment are:**



Write down your history, and include the following:

Timeline of symptoms

Previous treatments

Previous diagnostic tests & results (including SUC with report of 'contamination' or 'mixed growth')

**Ask your clinician** how they would like you to relay your information, ie., chronologically, a complete list of symptoms, etc. and try to stick to their preference. This completed guide will help prepare you for whichever method they prefer.

**Write a list of questions.** See examples from the previous section or develop your own.