

**2024**

# Urologic Diseases in America

**ANNUAL DATA REPORT**

**Urologic Chronic Pelvic Pain Syndrome**

April 26, 2024

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### Note

This document is one of the seven that collectively comprise the 2024 *Urologic Diseases in America: Annual Data Report (ADR)*. This document reports and discusses findings on Urologic Chronic Pelvic Pain Syndrome (UCPPS). Other topics in the 2024 ADR are Introduction and Methods; Benign Prostatic Hyperplasia and Associated Lower Urinary Tract Symptoms (BPH/LUTS); Urinary Stone Disease (USD); Urinary Incontinence (UI); Fournier's Gangrene (FG); and Healthcare Expenditures of Urologic Diseases. These analyses are available as separate documents on the UDA website. Additional details on the methodology and data sources are provided in Appendices A and B, respectively, in the Introduction and Methods document.

### Suggested citation

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# Urologic Chronic Pelvic Pain Syndrome

## Main Takeaways

- The claims-based annual prevalence of urologic chronic pelvic pain syndrome (UCPPS) from 2012 to 2021 ranged between 2 and 4 per 1,000 persons aged 18-64 years, and between 6 and 8 per 1,000 persons aged 65 years and older.
- UCPPS often co-occurred with lower urinary tract symptoms (LUTS) and chronic back pain; in 2021, the rates of these two comorbidities were greater than 50% and 35%, respectively, among patients aged 65 and older with UCPPS.
- Men with chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) aged 65 and older had an erectile dysfunction rate twice as high as that of the overall study population in the same age group (17% vs. 8%, in 2021).
- Opioid use remains high in the UCPPS population. In 2021, two out of five patients with interstitial cystitis/bladder pain syndrome (IC/BPS) or CP/CPPS aged 65 and older filled an opioid prescription.
- Prescriptions filled for antibiotics among men with CP/CPPS aged 65 and older declined from 67% in 2012 to 49% in 2021, while that for alpha-blockers remained stable.
- Among patients aged 65 and older with IC/BPS, on average 5% underwent hydrodistension annually from 2012-2021, while for those aged 18-64, 8% underwent the procedure.

## 1 Overview

Urologic chronic pelvic pain syndrome (UCPPS) is a common condition defined by chronic pain in the pelvic region or genitalia, often accompanied by diverse symptoms including urinary frequency and urgency.<sup>1</sup> In addition to physical pain and discomfort, UCPPS can have debilitating impacts on patients' emotional and social health. The syndrome can trigger fatigue, social isolation, negative mood changes, and sexual dysfunction.<sup>2</sup> This section summarizes the evaluation and management of UCPPS. Section 2 illustrates results on prevalence, incidence, comorbidities, prescription drugs filled, and procedure use; based on contemporary data on two age cohorts (see 2024 Methods document for details on databases and related methods). Section 3 discusses these results relative to the peer-reviewed literature on UCPPS.

UCPPS comprises interstitial cystitis/bladder pain syndrome (IC/BPS) in men and women and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) in men only. IC/BPS is a bladder condition that

may present with symptoms of urinary urgency, frequency, dysuria, and pelvic pain. CP/CPPS is a pain disorder in men that may present with pain in the perineum, penis, testicles or suprapubic region.<sup>3</sup> The diagnosis of UCPPS should encompass both a thorough history and physical examination. Additional tests, including laboratory tests and procedures, may be required to rule out other conditions.

Treatment is predominantly non-surgical. According to the American Urological Association (AUA) guidelines for IC/BPS, clinicians should initiate treatment with behavioral strategies. This includes educating patients about bladder function and informing them about the knowns and unknowns of the condition. Additionally, patients should be encouraged to adopt stress management practices and relevant pelvic floor physical therapy techniques. If behavioral interventions prove ineffective, clinicians may resort to pharmacological pain management. Oral medications such as amitriptyline, cimetidine, hydroxyzine, or pentosan polysulfate might be prescribed. Intravesical instillations with dimethyl sulfoxide (DMSO), heparin, or lidocaine may also be considered for some patients.

Men or women with UCPPS can be offered a range of prescription drugs to manage their symptoms. Opioids, muscle relaxants, and tricyclic antidepressants can be used for both IC/BPS and CP/CPPS. Additional options for IC/BPS include histamine H1/H2 receptor antagonists and immunosuppressants. CP/CPPS can also be treated with 5-alpha reductase inhibitors, alpha blockers, and antibiotics.

For patients who do not respond to conservative treatments, interventions like short-duration, low-pressure hydrodistension, botox injections, or neuromodulation may be beneficial. In rare cases involving end-stage bladder disease where all other treatments have failed; major surgery, such as ileal conduit diversion, may be an option. Selected procedures and pharmacological classes used in the analysis are shown in Table 1 below.

**Table 1. Selected procedure and pharmacological classes considered for UCPPS analysis**

Procedure (IC/BPS only)	Pharmacological Classes
<ul style="list-style-type: none"> <li>• Hydrodistension<sup>4</sup></li> </ul>	<ul style="list-style-type: none"> <li>• 5-alpha reductase inhibitor (CP/CPPS only)</li> <li>• Alpha blocker (CP/CPPS only)</li> <li>• Antibiotic (CP/CPPS only)</li> <li>• Muscle relaxant</li> <li>• Opioid</li> <li>• Tricyclic antidepressant</li> <li>• Histamine H1 receptor antagonist (IC/BPS only)</li> <li>• Histamine H2 receptor antagonist (IC/BPS only)</li> <li>• Immunosuppressant (IC/BPS only)</li> <li>• Pentosan polysulfate sodium (IC/BPS only)</li> </ul>

## 2 Results

### → Study population

Table 2 shows the total number of patients with UCPPS as well as the total population in each referenced cohort (age 18-64 in commercial insurance, age 65+ in Medicare fee-for-service) in 2021.

Table 2. Total number of patients with UCPPS, 2021

Population	Commercial Insurance Age 18-64			Medicare FFS Age 65+		
	Overall	Female	Male	Overall	Female	Male
Total	5,642,816	2,776,873	2,865,943	24,473,919	13,694,802	10,779,115
Patients with UCPPS	14,901	4,651	10,250	148,122	44,943	103,179
Patients with IC/BPS	5,006	4,651	355	50,216	44,943	5,273
Patients with CP/CPPS (men only)	9,997	N/A	9,997	98,725	N/A	98,725

### → Prevalence

The overall claims-based annual period prevalence of UCPPS from 2012 to 2021 ranged between 0.2% and 0.4% (2 and 4 per 1,000 persons) among those aged 18-64 and between 0.6% and 0.8% (6 and 8 per 1,000 persons) among those aged 65 and older. The prevalence of UCPPS among men aged 65 and older decreased from 1.5% to 1.0% between 2012 and 2021. The prevalence among women was approximately 0.3% over the same period. Similar trends were found for those aged 18-64 (Figure 1a). Prevalence of UCPPS was associated with age (Figure 1b).

Figure 1a. Claims-based prevalence of UCPPS, by year and gender-age group (2012-2021)

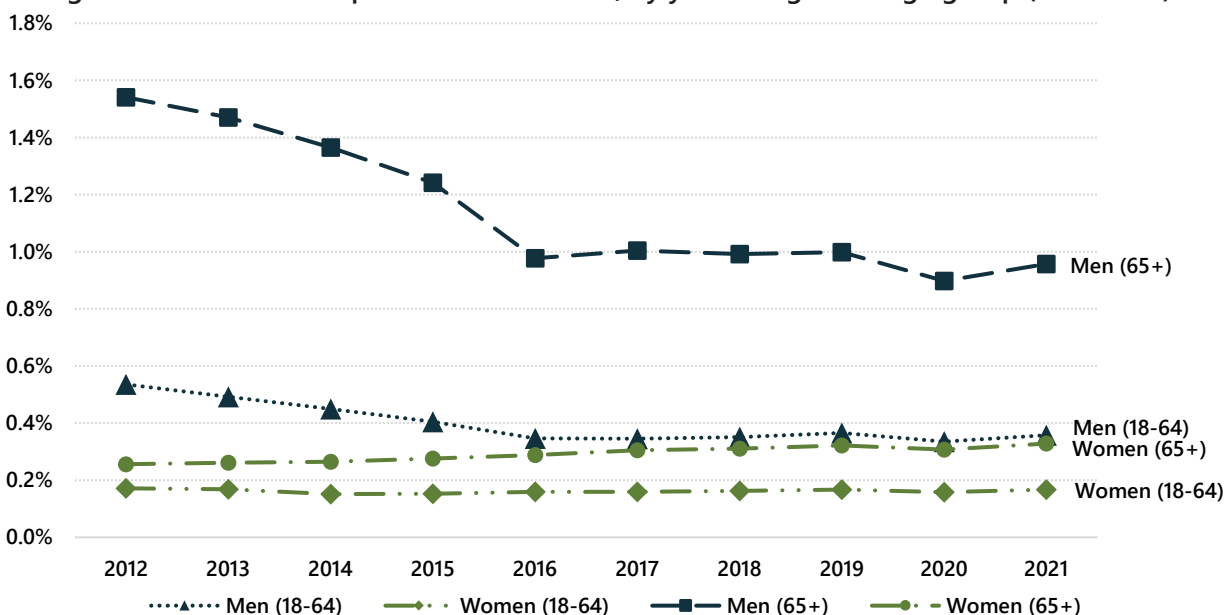
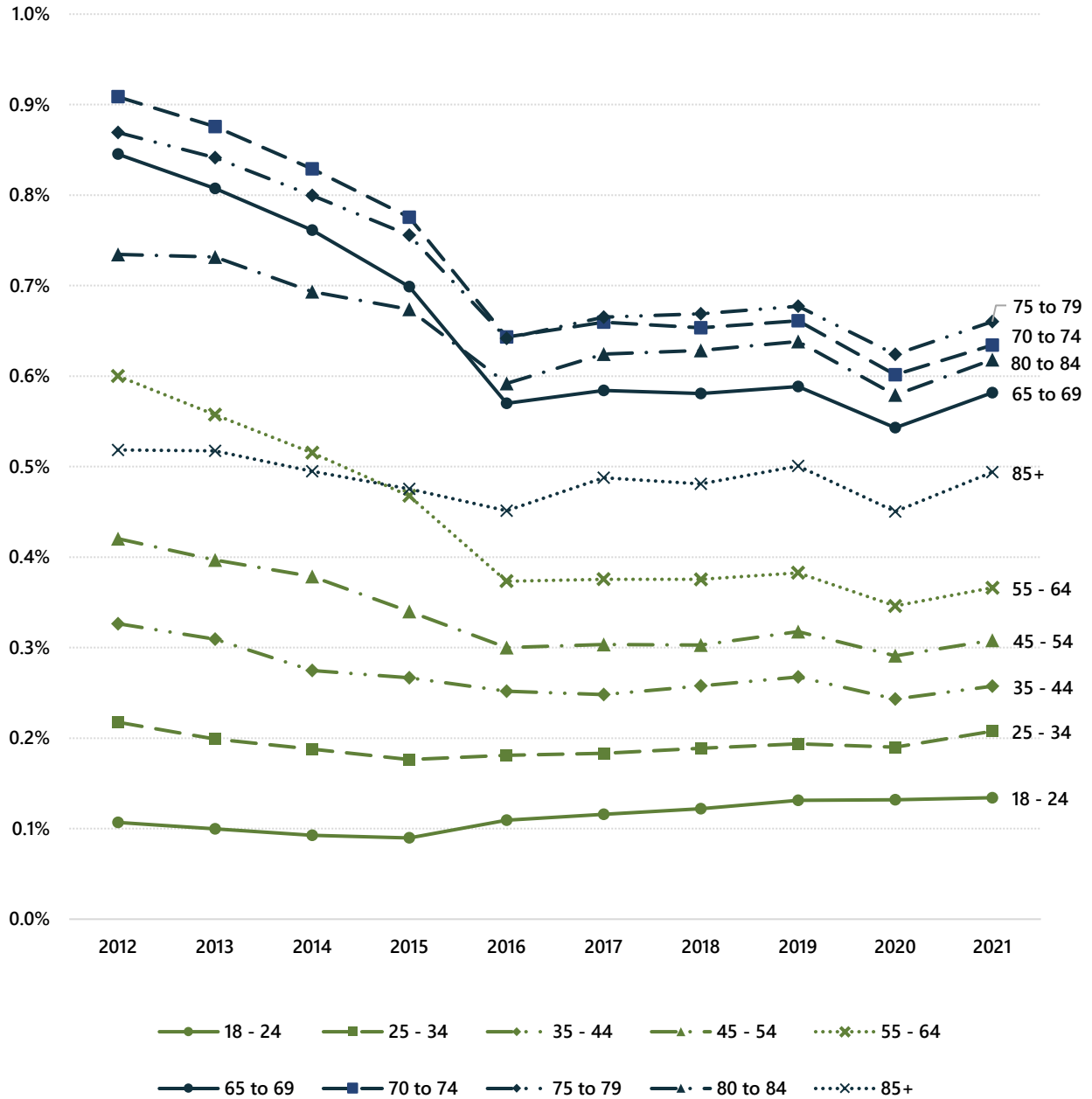


Figure 1b. Claims-based prevalence of UCPPS, by year and age (2012-2021)



Notes: The numerator denotes the number of patients with UCPPS in each year, by each referenced group. The denominator denotes the total number of persons in each referenced group in each year.

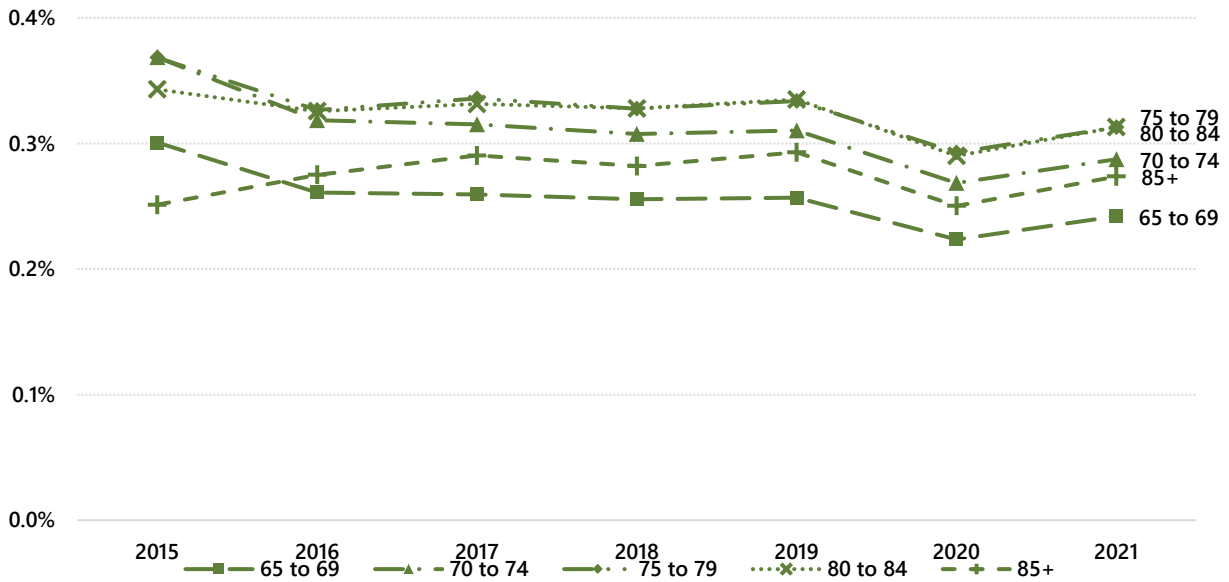
The annual prevalence of IC/BPS for patients aged 65 and older was approximately 0.3% among women and remained at 0.05% among men from 2012 to 2021. In the same study period, for those aged 18-64, prevalence was approximately 0.16% for women and remained at 0.01% for men. The prevalence of CP/PPS for men aged 65 and older ranged from 0.9% to 1.5%; prevalence declined throughout 2012-2021, but to a greater extent from 2012 to 2016. Similar trends were seen for those aged 18-64, with prevalence ranging between 0.3% and 0.5%.



## → Incidence

The incidence of UCPPS for patients aged 65 and older was 0.3% annually (3 per 1,000 persons) from 2015 through 2021. This amounted to approximately 68,300 patients aged 65 and older newly identified with UCPPS annually. Annual incidence ranged from 0.2% to 0.4% across age subgroups (Figure 2). Incidence was generally higher for older patients, with the exception of those aged 85 and older who had a slightly lower incidence compared to patients aged 70 to 74 in 2021.

Figure 2. Claims-based incidence of UCPPS, by year and age (2015-2021)



Notes: The numerator denotes the number of patients with incident UCPPS aged 65 and older in each year. The denominator denotes the total number of persons in each age cohort in each year.

The incidence of IC/BPS for patients aged 65 and older was 0.1% annually from 2015 through 2021, and was lower in men than women. This amounted to approximately 14,800 persons newly identified with IC/BPS annually. The incidence of CP/CPPS among patients 65 and older was 0.6% per year from 2015 through 2021. This amounted to approximately 56,300 persons newly identified with CP/CPPS annually.

## → Comorbidities

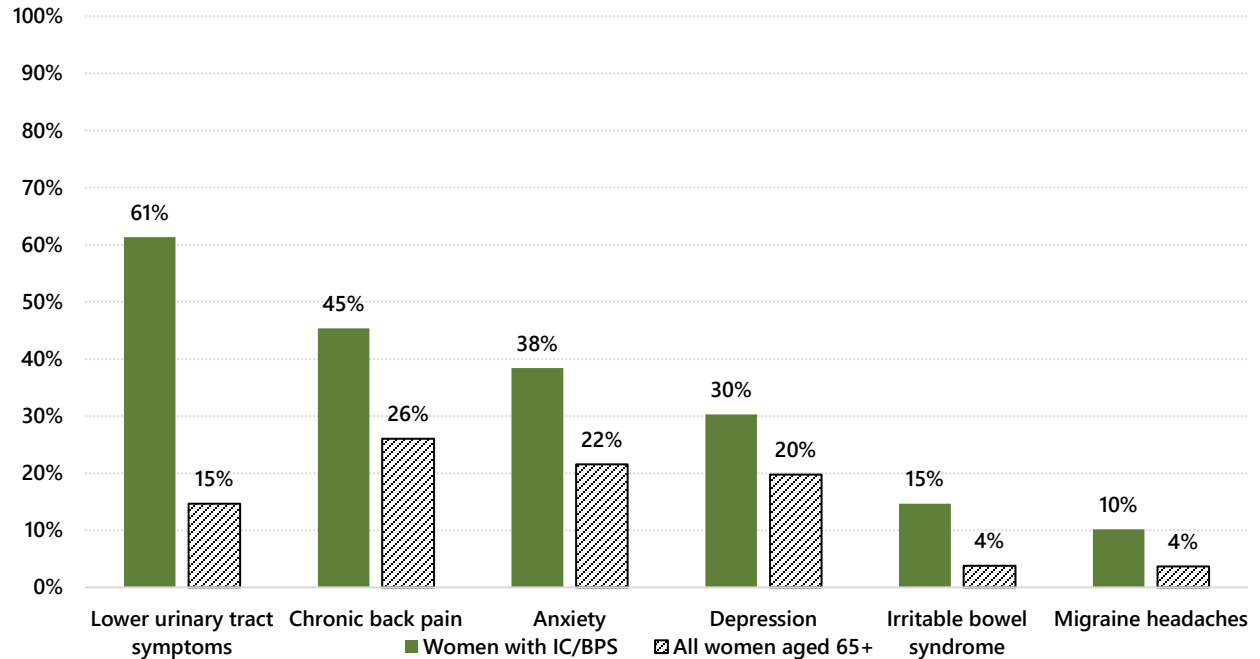
The prevalence and type(s) of comorbidities varied among patients with IC/BPS and CP/CPPS. In 2021, among women aged 65 and older with IC/BPS, lower urinary tract symptoms (LUTS; 61%), chronic back pain (45%), anxiety (38%), depression (30%), and migraine headaches (10%) were common comorbidities (Figure 3a). In the same year, among women aged 18-64 with IC/BPS, LUTS (68%), anxiety (48%), chronic back pain (35%), depression (30%), and migraine headaches (21%) were common comorbidities.

In 2021, among men aged 65 and older with IC/BPS, LUTS (64%), chronic back pain (38%), anxiety (24%), and depression (21%) were common comorbidities (Figure 3b). In the same year, among men

aged 18-64 with IC/BPS, LUTS (79%), chronic back pain (35%), anxiety (33%), depression (15%), and migraine headaches (5%) were common comorbidities.

In 2021, among men aged 65 and older with CP/CPPS, LUTS (54%), chronic back pain (40%), anxiety (20%), depression (17%), and erectile dysfunction (17%) were common comorbidities (Figure 3c). In the same year, among men aged 18-64 with CP/CPPS, LUTS (55%), chronic back pain (39%), anxiety (29%), erectile dysfunction (19%), and depression (16%) were common comorbidities.

**Figure 3a. Common comorbidities among women living with IC/BPS, age 65+ (2021)**



**Figure 3b. Common comorbidities among men living with IC/BPS, age 65+ (2021)**

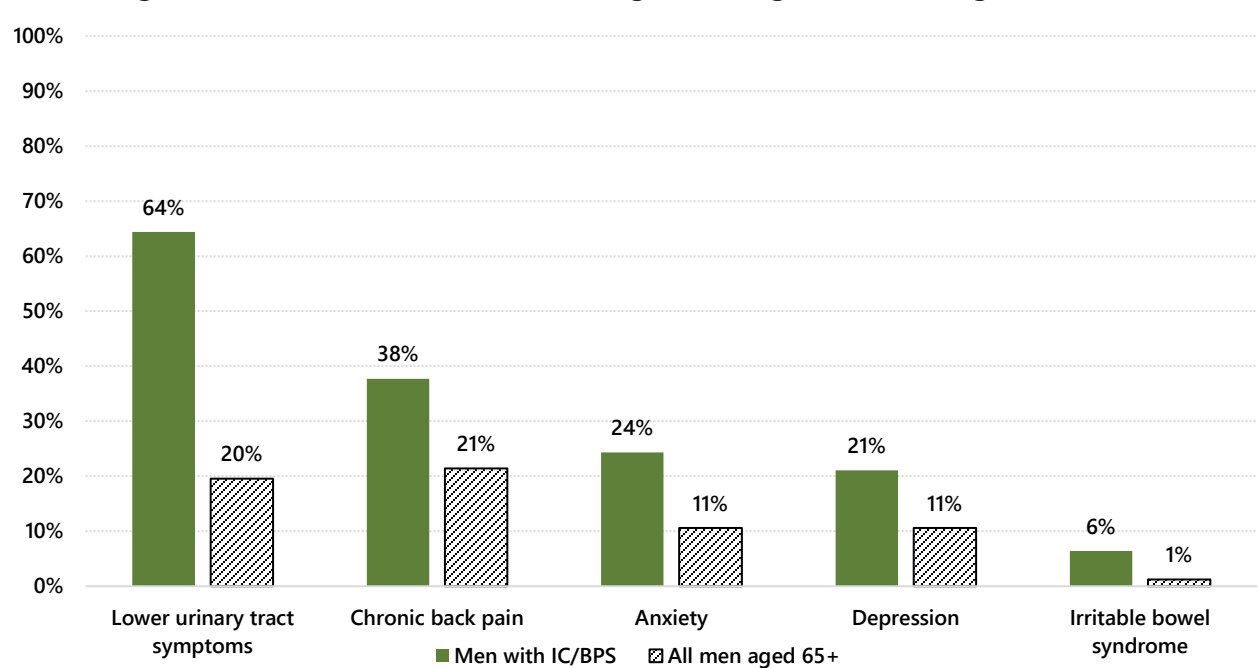
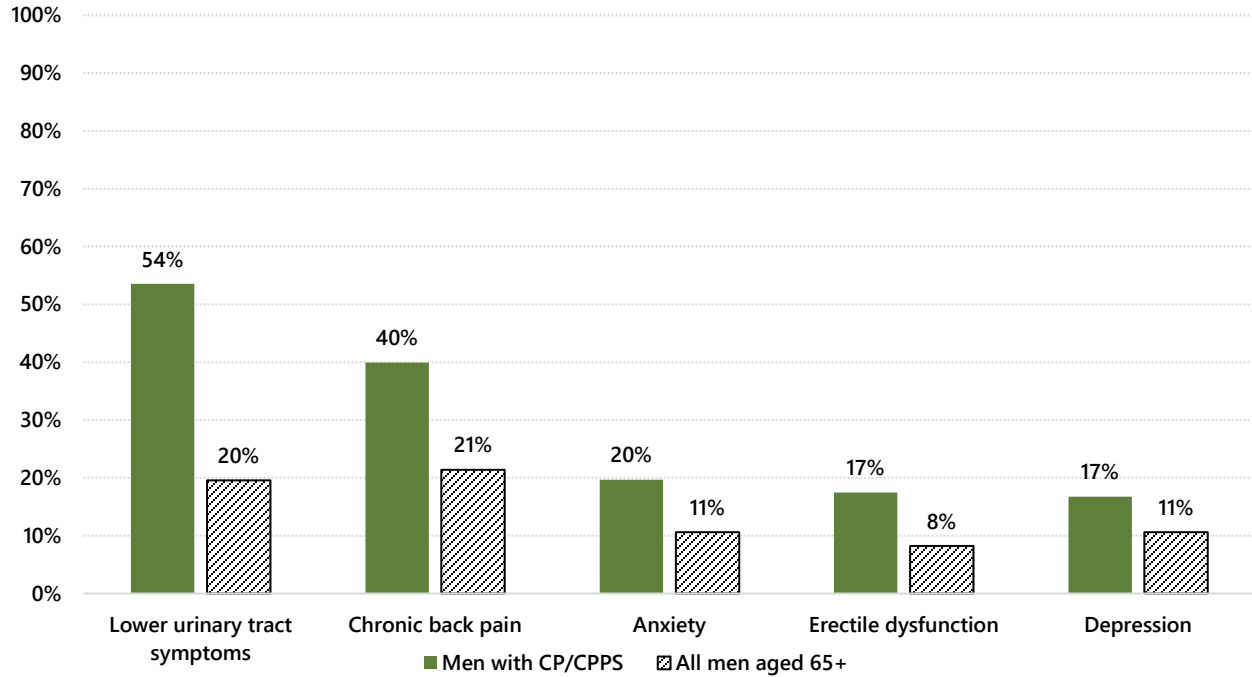


Figure 3c. Common comorbidities among men living with CP/CPPS, age 65+ (2021)



Notes: The numerator denotes the number of women with IC/BPS (panel a), men with IC/BPS (panel b), or men with CP/CPPS (panel c) aged 65 and older who were also identified with the comorbidity referenced in 2021. The denominator denotes the total number of women (panel a) or men (panels b and c) with the corresponding condition (solid column) and total number of women (panel a) or men (panel b and c) in the age 65+ cohort (patterned column).

### ➔ Prescription drugs

Overall, the percentage of patients aged 65 and older with IC/BPS who filled any of the studied drugs (see Table 1) decreased from 72% in 2012 to 57% in 2021. For those aged 18-64 with IC/BPS, that percentage declined from 77% in 2012 to 61% in 2021. Among patients aged 65 and older with CP/CPPS who filled any of the studied drugs, that percentage also decreased from 88% in 2012 to 83% in 2021. For those aged 18-64 with CP/CPPS, it declined from 83% in 2012 to 66% in 2021.

Among patients aged 65 and older with IC/BPS, the percentage of patients filling prescriptions for opioids and pentosan polysulfate sodium declined from 56% and 23% in 2012 to 40% and 7% in 2021, respectively (Figure 4a). Similar trends were seen for those aged 18-64. Among patients aged 65 and older with CP/CPPS, the percentage of patients filling prescriptions for antibiotics declined from 67% in 2012 to 49% in 2021 (Figure 4b). For those aged 18-64, the percentage of patients filling prescriptions for antibiotics declined from 71% in 2012 to 44% in 2021.

Figure 4a. Prescriptions filled among patients with IC/BPS, age 65+ (2012-2021)

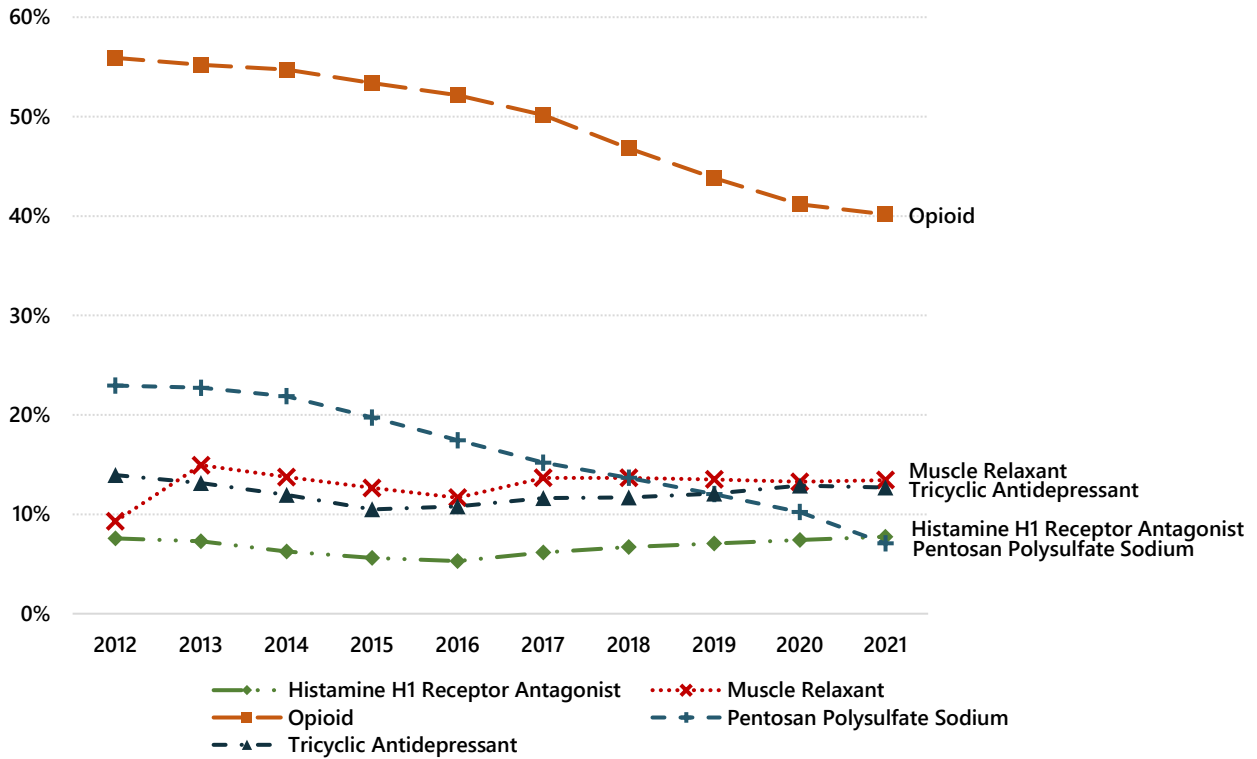
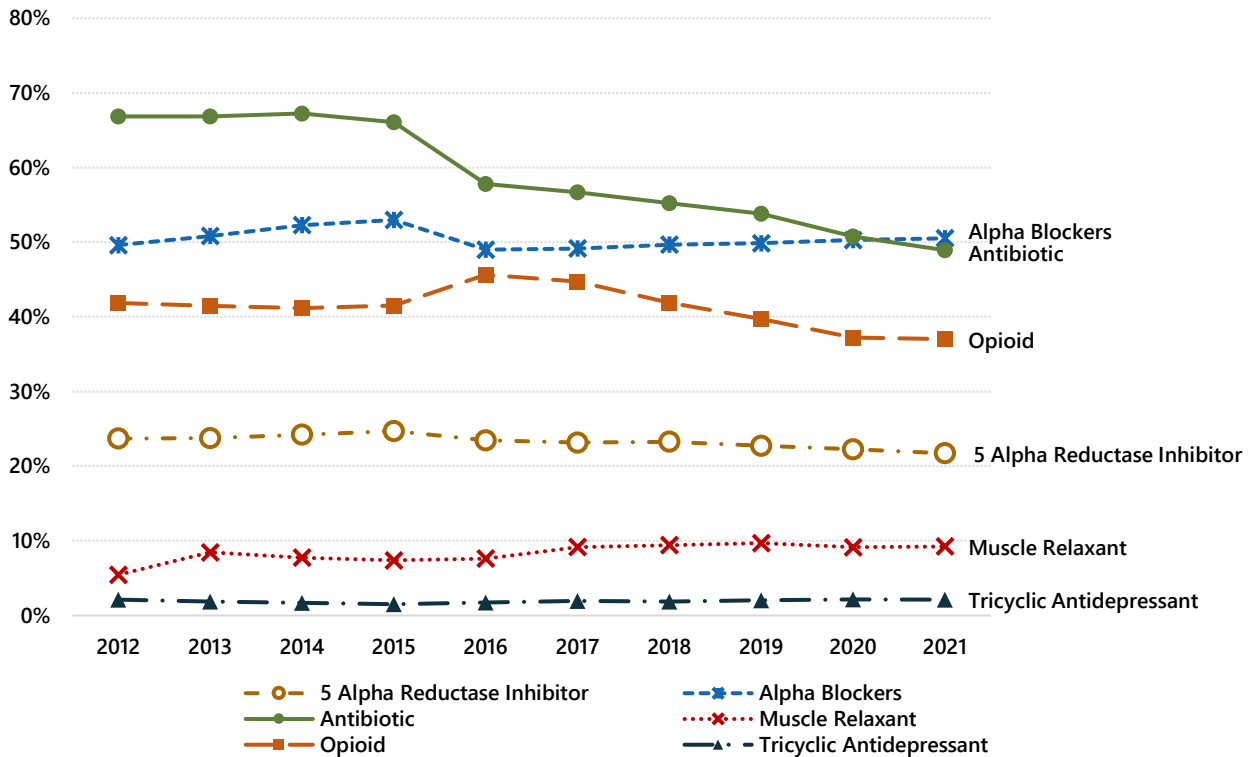


Figure 4b. Prescriptions filled among patients with CP/CPPS, age 65+ (2012-2021)

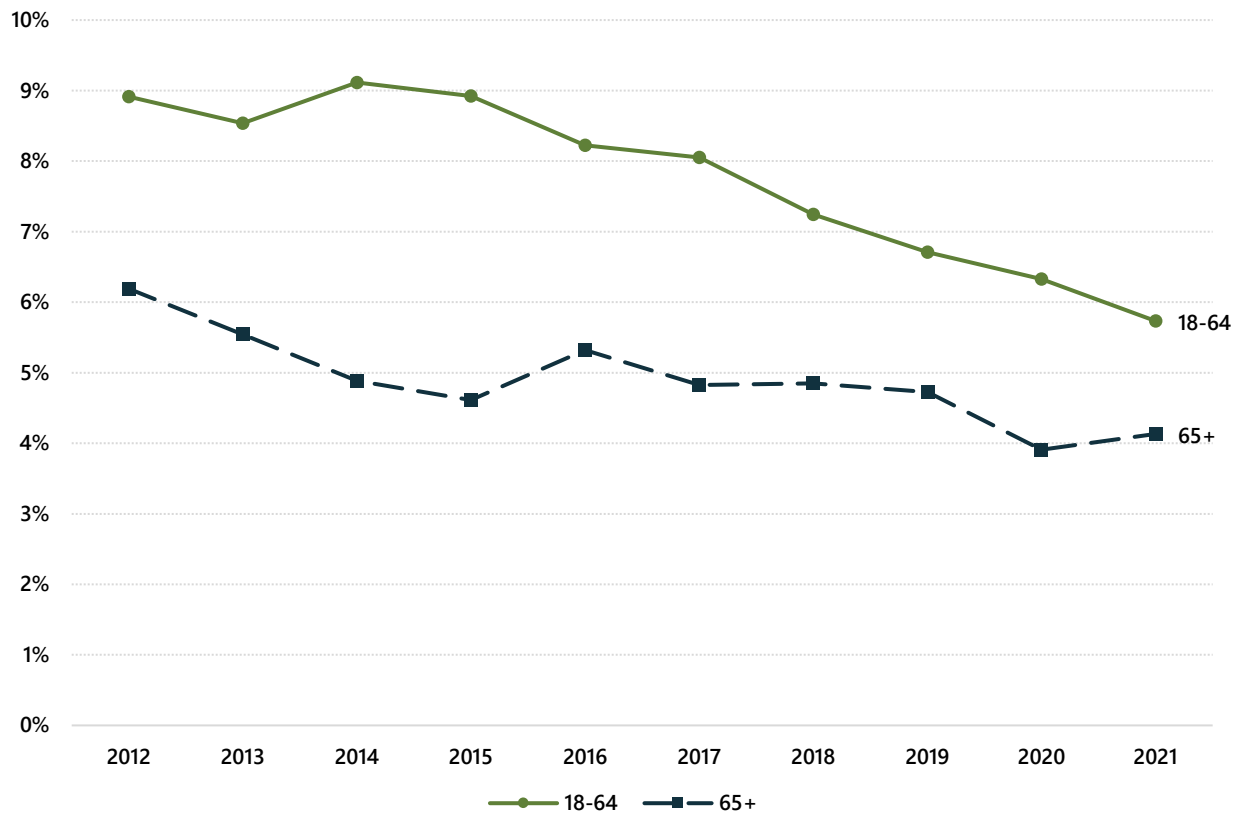


Notes: The numerator denotes the number of patients with IC/BPS (panel a) or CP/CPPS (panel b) aged 65 and older who filled the prescription referenced in each year. The denominator denotes the total number of patients aged 65 and older with each corresponding condition and full-time Part D enrollment in each year.

### → Hydrodistension procedure (IC/BPS only)

On average, between 2012 and 2021, 4.9% of patients aged 65 and older with IC/BPS underwent a hydrodistension procedure related to the condition. For those aged 18-64, 7.8% underwent the procedure. Both age cohorts experienced a decline in hydrodistension rates between 2012 and 2021 (Figure 5).

Figure 5. Percent of patients aged 65+ with IC/BPS who underwent hydrodistension (2012-2021)



Notes: The numerator denotes the number of patients with IC/BPS who underwent hydrodistension during 2012-2021, by age group and year. The denominator denotes the total number of patients with IC/BPS in each age group and year.

### 3 Discussion

This analysis yielded several key findings. First, the claims-based prevalence of UCPPS among individuals aged 65 and older was low, averaging 0.7% from 2012 to 2021 (for those aged 18-64, it was 0.3%). Second, UCPPS frequently co-occurred with LUTS, chronic back pain, depression, anxiety, and migraine headaches. Third, opioid use among UCPPS patients remained high. Lastly, there was a noticeable decline in the use of hydrodistension during the study period.

Annual prevalence of IC/BPS averaged around 0.3% for women and 0.1% for men aged 65 and older between 2012 and 2021; annual prevalence estimates of CP/CPSPS for men were 0.9%-1.5% from 2012 to 2021 for the same age cohort. These claims-based prevalence rates are lower than those

observed in survey-based studies.<sup>5</sup> For instance, a survey-based study estimated that among men, 1.9% to 4.2% have IC/BPS and 1.8% have CP/CPPS.<sup>6</sup> Further, the current analysis uses a narrow definition of UCPPS that tries to capture conditions specific to UCPPS, rather than a broader set of criteria that could reflect either UCPPS or other conditions. For example, in the specific definition of IC/BPS, the diagnosis code associated with “chronic interstitial cystitis” was included but the code for “other chronic cystitis” was excluded to minimize the risk of misclassifying a patient's condition. However, it is plausible that clinicians might code UCPPS using a broad range of diagnosis codes that overlap with other infectious, inflammatory, or pain conditions. Sensitivity analysis using a broader group of diagnosis codes suggests that prevalence would be higher, but would show similar trends.

Patients with IC/BPS and CP/CPPS both exhibited substantially higher rates of urologic symptoms, chronic back pain, mental health diagnoses, and headaches compared to the overall study population. These findings align with other studies that have explored comorbidities in patients with UCPPS.<sup>7</sup> One study found that the overlap rate of pain conditions is higher than that of other chronic medical conditions.<sup>8</sup> For example, results showed that men with CP/CPPS had an erectile dysfunction rate twice as high as the overall study population (17.4% vs. 8.2%). This finding aligns with the work done by the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network. In a recent study, members of the MAPP Research Network reported that, compared to healthy controls and patients with other chronic pain conditions, men with UCPPS experience greater degrees of sexual dysfunction, including both erectile and ejaculatory dysfunction.<sup>9</sup>

Opioids were found to be commonly prescribed for both IC/BPS and CP/CPPS. From 2012 to 2021, the use of opioids for both conditions declined. However, in 2021, two out of five patients with IC/BPS or CP/CPPS filled an opioid prescription. While we cannot definitively state that the opioid was prescribed specifically for these conditions, it's notable that opioid use remains high in the UCPPS population.

Regarding medication trends specific to IC/BPS, the use of tricyclic antidepressants, muscle relaxants, and histamine receptor blockers remained stable over the last decade. Meanwhile, the use of pentosan polysulfate sodium declined. Although pentosan polysulfate sodium is the only oral agent approved by the Food and Drug Administration (FDA) for the treatment of IC/BPS, the AUA found that high-quality trials conducted for this drug yielded mixed results. Furthermore, a meta-analysis revealed a clinically weak, relative risk ratio of 1.69.<sup>10</sup> Additionally, there are concerns about potential macular damage and vision-related injuries associated with the use of pentosan polysulfate sodium.<sup>11</sup> The possibility that the drug might only benefit a subset of patients, coupled with the risks associated with its use, could explain the decline in its use over time.

There were notable medication trends for men with CP/CPPS. The prescription of antibiotics for patients with CP/CPPS declined from 67% in 2012 to 49% in 2021. This may reflect a growing understanding of the condition, especially with insights from research groups like the National Institutes of Health (NIH) Chronic Prostatitis Collaborative Research Network. For instance, studies from this network revealed that ciprofloxacin and tamsulosin did not significantly reduce symptoms

in men with long-standing CP/CPPS. The continued use of alpha-blockers over time in this population could indicate a need for treatment of LUTS. However, research does not consistently support the efficacy of alpha-blockers, such as alfuzosin, in alleviating the symptoms of CP/CPPS.<sup>12</sup>

The percentage of patients undergoing hydrodistension for IC/BPS declined over time. The AUA guidelines support the use of cystoscopy under anesthesia with short-duration, low-pressure hydrodistension as a treatment option. However, this treatment modality is primarily supported by observational studies that revealed clinically significant relief of symptoms for a subset of patients that declined over time.<sup>13</sup> The lack of randomized control trials supporting its use may explain the decline in the use of the procedure over time.

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- <sup>1</sup> Clemens, J. Quentin, Chris Mullins, A. Lenore Ackerman, Tamara Bavendam, Adrie van Bokhoven, et al. 2018. "Urologic Chronic Pelvic Pain Syndrome: Insights from the MAPP Research Network." *Nature Reviews Urology* 16, no. 3: 187–200. <https://doi.org/10.1038/s41585-018-0135-5>.
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  - <sup>3</sup> Clemens, J. Quentin, Deborah R. Erickson, Norma P. Varela, and H. Henry Lai. 2022. "Diagnosis and Treatment of Interstitial Cystitis/Bladder Pain Syndrome." *The Journal of Urology* 208, no. 1: 34–42. <https://doi.org/10.1097/ju.0000000000002756>; Nickel, J. Curtis, Leroy M. Nyberg, and Mike Hennenfent. 1999. "Research Guidelines for Chronic Prostatitis: Consensus Report from the First National Institutes of Health International Prostatitis Collaborative Network." *Urology* 54, no. 2: 229–54. [https://doi.org/10.1016/s0090-4295\(99\)00205-8](https://doi.org/10.1016/s0090-4295(99)00205-8); Clemens, J. Quentin. 2023. "Interstitial Cystitis/Bladder Pain Syndrome: Clinical Features and Diagnosis." in *UpToDate*, ed. Ted. W Post (Waltham, MA: UpToDate). <https://www.uptodate.com/contents/interstitial-cystitis-bladder-pain-syndrome-clinical-features-and-diagnosis>.
  - <sup>4</sup> The current analysis on procedures does not cover the full span of procedures that may be relevant to UCPPS. These may include less common procedures like fulguration, ileal conduit, urinary diversion, and neuromodulation.
  - <sup>5</sup> Clemens, J. Quentin, Deborah R. Erickson, Norma P. Varela, and H. Henry Lai. 2022. "Diagnosis and Treatment of Interstitial Cystitis/Bladder Pain Syndrome." *The Journal of Urology* 208, no. 1: 34–42. <https://doi.org/10.1097/ju.0000000000002756>; Similar types of under-identification have been found in survey studies. One such analysis concluded that of the 2.7%–6.5% of United States adult women who meet IC/BPS criteria, only 9.7% of them are identified with IC/BPS. See Berry, Sandra H., Marc N. Elliott, Marika Suttorp, Laura M. Bogart, et al. 2011. "Prevalence of Symptoms of Bladder Pain Syndrome/Interstitial Cystitis among Adult Females in the United States." *The Journal of Urology* 186, no. 2: 540–44. <https://doi.org/10.1016/j.juro.2011.03.132>.
  - <sup>6</sup> Suskind, Anne M., Sandra H. Berry, Brett A. Ewing, Marc N. Elliott et al. 2013. "The Prevalence and Overlap of Interstitial Cystitis/Bladder Pain Syndrome and Chronic Prostatitis/Chronic Pelvic Pain Syndrome in Men: Results of the RAND Interstitial Cystitis Epidemiology Male Study." *The Journal of Urology* 189, no. 1: 141–45. <https://doi.org/10.1016/j.juro.2012.08.088>.
  - <sup>7</sup> Weissman, Myrna M., Raz Gross, Abby Fyer, et al. 2004. "Interstitial Cystitis and Panic Disorder." *Archives of General Psychiatry* 61, no. 3: 273. <https://doi.org/10.1001/archpsyc.61.3.273>; Buffington, C.A. Tony. 2004. "Comorbidity of Interstitial Cystitis with Other Unexplained Clinical Conditions," *The Journal of Urology* 172, no. 4 Part 1: 1242–48. <https://doi.org/10.1097/01.ju.0000137953.49304.6c>; Loh-Doyle, Jeffrey, Alisa J. Stephens-Shields, Renee Rolston, Craig Newcomb, et al. 2022. "Predictors of Male Sexual Dysfunction in Urologic Chronic Pelvic Pain Syndrome (UCPPS), Other Chronic Pain Syndromes, And Healthy Controls in the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network." *The Journal of Sexual Medicine* 19, no. 12: 1804–12. <https://doi.org/10.1016/j.jsxm.2022.08.196>.
  - <sup>8</sup> Schrepf, Andrew, Vy Phan, J. Quentin Clemens, William Maixner, et al. 2020. "ICD-10 Codes for the Study of Chronic Overlapping Pain Conditions in Administrative Databases." *The Journal of Pain* 21, no. 1–2: 59–70. <https://doi.org/10.1016/j.jpain.2019.05.007>.
  - <sup>9</sup> Loh-Doyle, Jeffrey, Alisa J. Stephens-Shields, Renee Rolston, Craig Newcomb, et al. 2022. "Predictors of Male Sexual Dysfunction in Urologic Chronic Pelvic Pain Syndrome (UCPPS), Other Chronic Pain Syndromes, And Healthy Controls in the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network." *The Journal of Sexual Medicine* 19, no. 12: 1804–12. <https://doi.org/10.1016/j.jsxm.2022.08.196>.
  - <sup>10</sup> Clemens, J. Quentin, Deborah R. Erickson, Norma P. Varela, and H. Henry Lai. 2022. "Diagnosis and Treatment of Interstitial Cystitis/Bladder Pain Syndrome." *The Journal of Urology* 208, no. 1: 34–42. <https://doi.org/10.1097/ju.0000000000002756>.
  - <sup>11</sup> Pearce, William A., Rui Chen, and Nieraj Jain. 2018. "Pigmentary Maculopathy Associated with Chronic Exposure to Pentosan Polysulfate Sodium." *Ophthalmology* 125, no. 11: 1793–1802. <https://doi.org/10.1016/j.ophtha.2018.04.026>.
  - <sup>12</sup> Nickel, J. Curtis, John N. Krieger, Mary McNaughton-Collins, Rodney U. Anderson, et al. 2008. "Alfuzosin and Symptoms of Chronic Prostatitis—Chronic Pelvic Pain Syndrome." *The New England Journal of Medicine* 359, no. 25: 2663–73. <https://doi.org/10.1056/nejmoa0803240>; Alexander, Richard B., Kathleen J. Probert, Anthony J. Schaeffer,



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J. Richard Landis, et al. 2004. "Ciprofloxacin or Tamsulosin in Men with Chronic Prostatitis/Chronic Pelvic Pain Syndrome: A Randomized, Double-Blind Trial." *Annals of Internal Medicine* 141, no. 8 : 581.  
<https://doi.org/10.7326/0003-4819-141-8-200410190-00005>.

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<https://doi.org/10.1016/j.juro.2006.09.029>.