

Victorian Government Inquiry into Women's Pain: Submission from Chronic UTI Australia

On behalf of Chronic UTI Australia, the sole national patient advocacy group dedicated to urinary tract infection (UTI), I am writing to share the experiences of an under-recognised group of women who endure life-altering chronic pelvic pain. Their condition is caused by a lack of understanding and mismanagement of an infection so common that it will affect one in two women at least once in their lifetime. Their suffering is unnecessary — this condition is treatable.

The concerns documented in this submission will no doubt add to a wealth of evidence presented to your Inquiry about how women's pain, and especially pelvic pain, is minimised in our society and our healthcare system. Moreover, chronic UTI is one of several health conditions predominantly affecting women that have been neglected in medical research and development.

While conditions such as endometriosis and pelvic mesh injury are finally getting the attention they deserve, the longstanding underfunding of UTI research, and the failure to translate research evidence into clinical practice, forces women to live with severe pain that is all-too-often dismissed, misdiagnosed and treated in inappropriate and potentially damaging ways.

Severe pain and quality-of-life impacts for women with chronic UTI

"... [chronic UTI] kept me trapped in my house and in such excruciating pain I planned my own death" – 'Hearing Patient Voices' survey participant

"I feel so incredibly alone with this condition, trapped in a vortex of pain with no lifeline or way out" – 'Hearing Patient Voices' survey participant

Chronic UTI Australia's *Hearing Patient Voices* survey report, which can be accessed at <https://www.chronicutiaustralia.org.au/survey/>, documents findings from our online survey of 410 people with chronic UTI symptoms. Participants were 396 women, 11 men and three non-binary/gender diverse people aged 19 – 84 years.

In contrast to the frequent characterisation of UTI as a trivial and easily treated condition, our survey showed that people with chronic UTI suffer serious quality-of-life impacts, typically for years and sometimes for decades. In the worst cases, people become housebound, lose their livelihoods and close relationships, and see little hope for the future.

Approximately half of our *Hearing Patient Voices* survey participants rated their pain, at its worst, as 'excruciating, unbearable' (9 on a 10-point pain scale) or 'unimaginable, unspeakable' (10 on a 10-point pain scale). The average rating was 7.9 out of ten, indicating pain in the upper range between 'very intense' and 'utterly horrible.' More than 90% of participants also struggled with urinary frequency. This can be so severe that it keeps people housebound and unable to sleep.

Several participants mentioned that they had experienced serious physical health complications, such as kidney infection, sepsis, and pregnancy loss, due to untreated or poorly treated chronic UTI.

When asked to rate the effect of chronic UTI on their lives 'overall', most participants (93.7%) indicated at least a moderate impact and half (49.3%) indicated an 'extreme' impact on their lives overall. Among the 15 specific life domains we enquired about, the most heavily impacted were 'sex life', 'ability to feel good about yourself', 'mental and emotional health', 'ability to exercise', 'sleep' and 'relationship with partner'. Consistent with the severe distress caused by their chronic UTI symptoms, our participants had markedly worse mental and emotional health than age and gender matched people in the general population.

In answer to an open-ended question, one in ten participants (9.7%) volunteered — without prompting — that the condition had left them feeling suicidal or that they had planned or attempted to take their own lives because of the condition. Sadly, international chronic UTI communities are aware of several completed suicides among their members.

While there have been few other studies specifically exploring the impacts of chronic UTI, a recent comparative qualitative study on experiences of women with endometriosis and other forms chronic pelvic pain found that:

“Women, regardless of the cause of their CPP [chronic pelvic pain], reported significant impacts on their intimate relationships, fertility, and parenting but those with non-endometriosis CPP often reported greater trouble communicating about pelvic pain in the workplace due to the “taboo” nature of discussing their vulval pain. Many participants described how a societal normalisation of pelvic pain resulted in women silencing their experiences, rendering their pain invisible. While women wanted to resist such silencing through information and support seeking, women with non-endometriosis CPP described fewer avenues to accessing credible informational resources or networks for support.”ⁱ

Medical misogyny and ignorance

“[I’ve] been told it was all in my head as I returned a negative test result.” – Hearing Patient Voices’ survey participant

“[It was suggested that I’m] someone who may be addicted to pain medication claiming to be in excruciating pain...” – Hearing Patient Voices’ survey participant

“It is a horrible feeling to not be believed or listened to when you are suffering beyond belief”. – Hearing Patient Voices’ survey participant

The distress caused by chronic UTI symptoms is often compounded by health professionals’ lack of understanding and inability to diagnose and treat the condition, as discussed in the next section. Further, findings from our *Hearing Patient Voices* survey show that women with chronic UTI are often poorly treated in the health system.

Staggeringly high numbers of participants in our survey had experienced negative interactions with health professionals. More than eight in ten felt that their symptoms had been dismissed or not believed by a healthcare professional. Many had been told that their symptoms were related to another (non-UTI) condition, or to their own behaviour. More than two thirds of participants (67.1%) had been offered or given therapies they believed were inappropriate and/or unhelpful, while about two thirds (64.4%) had been told by a healthcare professional that nothing could be done for their symptoms.

While in most cases the behaviour of health professionals appeared to have stopped short of outright hostility, a few participants recounted troubling examples of being openly belittled and subject to verbal aggression. Included in this category were accounts of doctors who had refused to continue treating the women and those who told their patients they would ‘just have to live with’ chronic UTI symptoms.

More than three quarters (76.8%) of participants agreed or strongly agreed with the statement ‘I have been given unhelpful advice to change my behaviour.’ Along with advice that was merely ill-informed (such as being told to drink more water and sit on the toilet longer), some participants reported that health professionals had made insensitive and inappropriate comments about their (presumed) sexual practices and lack of hygiene. One participant wrote:

‘[I] was told that I had too many sexual partners (I’ve been in a long-term relationship for 14 years) and told that I have bad hygiene – which I do not.’

Most concerningly, 17.3% of survey participants had received a mental health ‘diagnosis’ to explain their symptoms. As we discuss in our survey report, attributing chronic pain or other unexplained physical symptoms to a mental health or emotional problem is alive and well in healthcare settings, despite now being widely condemned as a form of ‘medical gaslighting.’

Several survey participants attributed their negative experiences of seeking help from doctors to the existence of “medical misogyny”. Similarly, urogynaecology consultant Rajvinder Khasriya, who works at the National Health Service’s Whittington Hospital’s Lower Urinary Tract Service in north London (a treatment centre offering specialist care for chronic UTI), believes these experiences are underpinned by a “*cultural normalisation of female pain*”. She says, “*There is a wider issue here, which is about access to healthcare for women, and the barriers they face.*”ⁱⁱ

Outdated and inadequate diagnosis and treatment of UTI

“It’s been 70 years, and we still don’t have a better diagnostic for UTIs and many UTIs are missed. Why is this? I think it’s a problem because this is primarily a disease of women.” – Professor Jennifer Rohn, University College London

Reliance on flawed UTI tests, despite well-established evidence of their failures

Medical guidelines for UTI diagnosis and treatment generally require a positive dipstick and midstream urine (MSU) culture. However, despite being widely considered the ‘gold standard’ and relied on in clinical practice, there is extensive scientific evidence of the inaccuracy of these routinely used UTI tests.

Although fast, cheap and readily used by practitioners as a basic first-line diagnostic tool, urine dipsticks are grossly insensitive and miss up to 70 % of infections.^{iii iv} A study by Khasriya et al concluded:

“Despite official guidelines and widespread use, these tests cannot be considered appropriate for diagnosing urinary tract infection in patients with lower urinary tract symptoms and should be abandoned in this context.”^v

Similarly, the unreliability of MSU cultures and unsuitability for the purpose of diagnosing UTI has been highlighted by numerous research groups around the world, going back several decades.^{vi vii viii ix x xi xii xiii} A 2016 study comparing standard urine culture with an expanded spectrum culturing technique concluded that, compared to the enhanced quantitative urine culture, standard urine culture missed 67% of all uropathogens, including 88% of non-E. coli uropathogens.^{xiv}

These standard tests are especially unsuitable for detecting infections that have become embedded in the bladder wall, as happens when a chronic UTI forms. Research published in *Science Advances* in 2023 found that bacteria form pods within the bladder wall and that current methods of diagnosing these infections are inadequate, as the bacteria is embedded and is not detected in a urine sample.^{xv}

Consistent with this evidence, 92.7% of our *Hearing Patient Voices* survey participants had returned a negative urine culture test while experiencing UTI symptoms. This usually meant they were denied antibiotic treatment, despite having clinical symptoms and a personal history consistent with UTI.

Lack of awareness of chronic UTI and its treatment

Many medical professionals do not acknowledge that chronic UTI exists. Despite being well described in the scientific literature, chronic UTI is not mentioned in Australia's current UTI guidelines, and there is no guidance for doctors on its treatment.

Currently, the only scientifically backed treatment for chronic UTI requires a constant level of full dose, first-generation antibiotic in the urine, supported by a urinary antiseptic (methenamine hippurate, also known as Hiprex), over a protracted period until symptoms clear.^{xvi xvii} The treatment approach prevents embedded bacteria from escaping, reinfecting and colonising new cells that line the bladder/urinary tract. The treatment period for chronic UTI varies between patients. Research has shown that the mean (average) treatment length following a specific protocol was 383 days.^{xviii}

There are currently no clinics in Australia specialising in diagnosing and treating this form of UTI, and many women experiencing chronic UTI have great difficulty accessing effective treatment. Most *Hearing Patient Voices* survey participants (82.6%) agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and can treat chronic UTI.

Survey participants who received antibiotics often did so only intermittently or at low (prophylactic) doses – treatment approaches now believed to worsen the condition.^{xix} Indeed, experts suspect that the formation of chronic UTI happens when the short (usually three to five day) courses of antibiotics prescribed for acute (one-off) and recurrent infections fail to kill off enough bad bacteria, leaving some to become embedded in the body. Once embedded, bacteria are difficult to pick up with traditional tests (as described above) and difficult to treat with short-term or low dose antibiotics.

Health professionals' frequent lack of understanding that UTI tests can be inaccurate, and lack of awareness of chronic UTI, leads to misdiagnosis and ineffective, sometimes harmful, medical, and surgical treatments. As well as the potential for worsened UTI symptoms and other complications through withholding of effective treatment, Chronic UTI Australia is concerned that many women – even those who eventually find a medical practitioner to help them – lose trust in the medical profession generally. The profound anxiety that some of our survey participants had developed about interactions with doctors could have long term repercussions in terms of their willingness to engage with the medical profession about their future health needs.

A growing avoidable burden on the health system

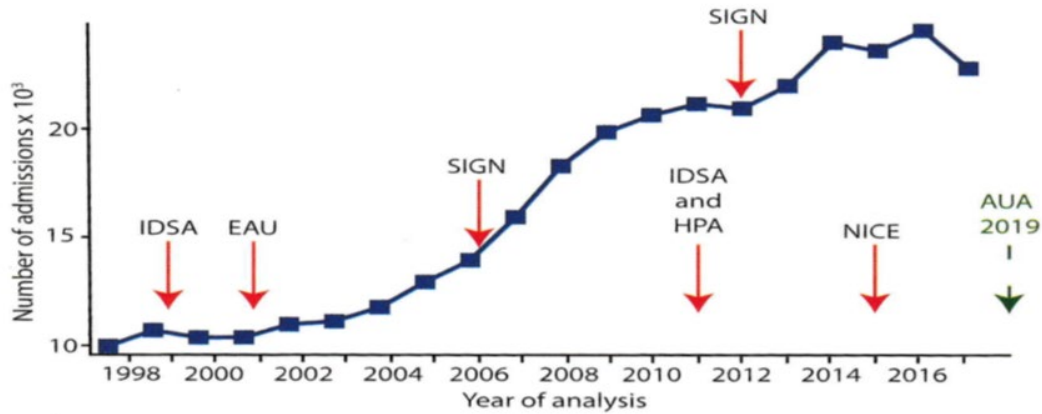
Urinary tract infection is very common. One two women and one in twenty men will have a UTI at least once in their lifetime.^{xx} UTI also affects babies, children, men and especially elderly people.

Unfortunately, there are few data on the number of people who experience problematic recurrent and chronic UTI. We do know, however, that there are frequent treatment failures using current treatment guidelines for acute UTI. For example, it has been estimated that approximately one quarter to one third of patients treated according to the United Kingdom's NICE guidelines have urine infections that fail treatment.^{xxi xxii} Among healthy young women who suffer from their first UTI, the risk of recurrence within six months is 24%. If they have a history of one or more UTIs, the risk of recurrence rises to 70% in that same year.^{xxiii}

There are growing concerns that attempts to restrict prescriptions for antibiotics and the length of antibiotic courses (due to concerns about antibiotic overuse) are doing more harm than good.^{xxiv} To summarise this research, repeated administration of 'sub-lethal' (short and low-dose) antibiotic treatments may be leading to a growing problem of antimicrobial resistance and more serious infections.

Concerns about an increase in serious UTI are supported by data showing growing rates of hospital admissions and emergency department presentations for UTI-related conditions. The figure below shows the increase in the United Kingdom's National Health Service (NHS) admissions for all cystitis diagnoses between 1998 and 2017 and its relationship to professional guidelines promoting shorter courses of antibiotics.^{xxv} Other British data show a 54% increase in hospital emergency department admissions for UTI between 2012 and 2016 and a 34% rise in diagnoses of urosepsis.^{xxvi} Similarly, data from the Australian Institute of Health and Welfare (AIHW) show that Australian UTI-related hospital admissions increased by nearly 82% between 1998 and 2017.^{xxvii} ¹ Data from the United States collected over 12 years (1998-2011) show a 52% increase in hospitalisations for UTI. The rate of increase was seen in both men and women but was significantly larger among women and elderly patients.^{xxviii}

¹ Chronic UTI Australia is currently seeking updated data from the Institute of Health and Welfare.



- IDSA Infectious Diseases Society of America
- EAU European Association of Urology
- SIGN Scottish Intercollegiate Guidelines Network
- HPA Health Protection Agency
- NICE National Institute for Health and Care Excellence
- AUA American Urological Association

Figure 6.4. NHS admissions for all cystitis diagnoses 1998 to 2017.

This figure has combined the admissions figures under a chronic cystitis umbrella and the notable rise in the incidence of these events is well shown. We have included the points where guidelines on cystitis have been published. They all perseverate, promoting short antibiotic courses for acute UTI with no consideration of the known failure rates. It seems that the advice for managing disappointing outcomes is to go by the cultures which have a high probability of being negative.

Figure 1: National Health Service (United Kingdom) admissions for all cystitis diagnosis, 1998 to 2017, Source: Cystitis Unmasked, TFM Publishing Ltd, 2021

The growing number of people with serious UTI are likely to constitute a high ‘burden’ on the health care system. Comparison of our *Hearing Patient Voices* survey participants in Australia with a general population sample showed a striking pattern of much higher health service utilisation among people with chronic UTI symptoms. The differences were most pronounced for resource intensive services, such as medical specialists, hospitalisations, and emergency department visits. Participants were almost three times more likely to be admitted to hospital or to have seen three or more health professionals in the previous 12 months. While our survey data are not suitable for gauging the extent of Australian health costs due to chronic UTI, they suggest a high level of potentially avoidable expenditure.

Media coverage and support from top Australian doctors – but no action yet for chronic UTI patients

In February this year, chronic UTI featured as a front-page news story in the Weekend Australian and as a feature article in The Weekend Australian Magazine.^{xxix} The articles describe many of the same issues raised in this submission. They feature several prominent health professionals – including the President of the Urological Society of Australia and New Zealand (USANZ) and the President of the Australia Medical Association (AMA) – highlighting the need for changes in UTI information, diagnostics and treatment, and better recognition and understanding of chronic, embedded infections.

Since the articles in The Australian were published, Chronic UTI Australia representatives have supported and been interviewed for the following media stories:

- The Project, [gender pain bias story](#)
- The Project, [chronic UTI feature](#)
- [The Guardian](#)
- ABC news radio (no link available)
- www.joincito.com.au/feed, UTI article by journalist Paula Goodyer (still to be published)
- CSIRO – interview for AMR platform on CSIRO website (article not yet finalised).

Following their participation in a roundtable organised by Chronic UTI Australia in May this year, the USANZ President, the AMA President and a representative of the Royal Australian and New Zealand College of General Practitioners (RANZCGP) have collaborated on an article for MJA (Medical Journal of Australia) Insight. While the article has not yet been published, we believe it calls for an urgent paradigm shift by the medical profession when it comes to UTI and endorses our concerns about lack of recognition of chronic UTI, and problems with its diagnosis and treatment.

However, the growing recognition of chronic UTI and medical leaders' statements of support for the position of Chronic UTI Australia have not yet resulted in on-the-ground changes that will benefit people suffering from this condition.

Chronic UTI Australia is contacted with depressing regularity by women whose doctors deny the existence of chronic UTI and the fallibility of standard UTI tests; who have been misdiagnosed or told that nothing can be done about their pain; and who believe – probably correctly – that their embedded infections have been caused by inappropriate treatment of acute and recurrent UTI.

Apart from our own website, accurate information about chronic UTI diagnosis and treatment is not available to Australian women or most doctors. The various UTI guidelines that exist in Australia ignore the scientific evidence about the failures of dipstick and culture tests, fail to offer evidence-based advice for doctors treating recurrent UTI, and fail to mention chronic UTI at all. Nor are there any clear referral pathways to specialist treatment for the significant number of women who are failed by standard primary care diagnosis and treatment for UTI, and who go on to develop life-changing chronic infections.

What the Victorian Government could do to advance its women's health agenda and stem this growing public health crisis

A growing body of international evidence suggests that problems with the diagnosis and treatment of UTI are leading to more serious, difficult-to-treat infections. In this submission, Chronic UTI Australia has shown that people, mainly women, who develop chronic, embedded infections:

- experience severe pelvic pain and other life-changing impacts
- feel let down by standard UTI tests that fail to detect their infections, and antibiotic prescribing practices that both contribute to and fail to eradicate chronic, embedded infections
- have great difficulty finding health care professionals who acknowledge, understand and appropriately treat chronic UTI – and are instead often dismissed, misdiagnosed and/or subject to ineffective and potentially damaging treatments
- are admitted to hospital and use other healthcare resources at much higher rates than the general population, creating an avoidable burden on patients and the health system.

Turning the tide on this situation requires action from healthcare professional bodies, researchers and research funders, and government agencies – all in collaboration with patients and their representatives.

The Victorian Government has a stake in the response to this public health crisis by virtue of its interest in the health and wellbeing of Victorian women, and through its funding and governance responsibility for the state's public health services. Chronic UTI Australia respectfully calls on the government to take the following priority actions as part of its women's health agenda:

- **Fund one or more specialist clinics** dedicated to chronic and other forms of recalcitrant UTI. Currently, unlike the United Kingdom and some other countries, there are no such clinics in Australia. Many Australian chronic UTI patients – those who can afford it – travel to or access online consultations from specialists associated with the National Health Service's UTI clinic in London. This clinic is increasingly overwhelmed with referrals and has long waiting times for appointments. In Victoria, we have world-class researchers and clinicians at Monash University and The Alfred Hospital who would like to establish Australia's first specialist UTI clinic. The availability of specialist chronic UTI diagnostics and treatment in Australia would respond to scientific research showing that chronic UTI is a distinct condition requiring specific, evidence-based diagnostic and treatment approaches. If funded, the clinic would also provide much needed Australian research and data to improve future UTI diagnostics and treatment approaches.
- **Educate the public and medical professionals** by publishing evidence-based, patient-centred and co-designed information about UTI, including chronic UTI.² The Department of Health's Women's Health Branch invited Chronic UTI Australia to review the content on urinary tract infection on the Victorian Government's Better Health Channel. In February this year, we provided detailed feedback and, where appropriate, replacement

² This could build on the recently updated website of the United Kingdom's National Health Service (NHS), which has recently provided official advice on chronic UTI. The NHS webpage for UTIs now includes a section explaining that current tests do not always pick up chronic infections; that they are caused by bacteria embedding into the bladder lining; and that they require specialised treatment approaches. See <https://inews.co.uk/news/nhs-updates-official-advice-chronic-uti-pressure-campaigners-2552776>

text to align the current content with the best available evidence. However, we are not aware of any plans to update the Better Health Channel content on UTI.

- Ensure that **knowledge and expertise in complex UTI management is included in the 20 new women's health clinics, and the dedicated Aboriginal-led women's clinic**, pledged by the Victorian Government (see <https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program>). This would ensure that chronic UTI is considered as a possible source of persistent pelvic pain in women with appropriate symptoms.
- Advocate to the Commonwealth Government for:
 - funding and support for **a comprehensive review of current UTI testing and treatment guidelines**, with a view to developing **new national guidelines** that are consistent with contemporary scientific evidence
 - **increased funding for UTI research**, especially applied and translational research aimed at bringing better diagnostic tests and therapeutics to market
 - **better collection of UTI information**, including on chronic UTI, in Australia's hospital and primary care data collections.

Representatives of Chronic UTI Australia would welcome the opportunity to meet with Department of Health staff responsible for the Inquiry into Women's Pain, or to provide further information via email. I can be contacted at deirdre@chronicutiaustralia.org.au or on 0400-021-962.

Yours sincerely



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ENDNOTES

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