



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Submitter: Name withheld

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This submission is made by [REDACTED], a Canberra resident who has lived with chronic embedded urinary tract infection (chronic UTI) for nine years. [REDACTED] experience highlights serious gaps in recognition, diagnosis, and treatment of chronic pelvic and urogenital pain conditions in the ACT, and is directly relevant to all terms of reference of this inquiry.

Personal experience and barriers to diagnosis (TOR 1 & 2)

For almost a decade, [REDACTED] has experienced daily pain, urinary urgency and frequency, fatigue, and substantial disruption to work, social life and mental health due to chronic UTI. During this time, many doctors in Canberra dismissed her symptoms as anxiety, overactive bladder, “normal” female issues, or simply unexplained, rather than investigating chronic infection as a cause. The underlying problem appears to be that chronic UTI is under-recognised in Australia and is often not captured by standard urine testing, leading to false reassurance and delays in care.

Because local clinicians did not acknowledge chronic UTI as a valid diagnosis, [REDACTED] had to travel repeatedly to Sydney and once to London(UK), at considerable personal cost, to seek care from clinicians with specific expertise in chronic infection and pelvic pain.

Access to effective treatment and international practice (TOR 2 & 3)

In searching for answers, [REDACTED] ultimately came under the care of Professor James Malone-Lee in the United Kingdom, a leading figure in chronic UTI research and treatment, and remained his patient until his death in 2024. She is now under the care of his son, who continues this work. The approach pioneered in that clinic involves:

- Careful symptom-based assessment rather than relying solely on standard dipstick or mid-stream urine tests¹.
- Long-term, targeted antibiotic therapy combined with close monitoring of response and side effects.

This long-term antibiotic approach is increasingly gaining acceptance in the UK as a reasonable option for selected patients who have failed standard short-course therapies and whose quality of life is severely impaired. There are specific [UK NHS guidelines](#). In contrast, Australian doctors, including many in Canberra, remain reluctant to consider long-term antibiotics even when patients have exhausted other

¹ Since the 1980s, peer-reviewed research has shown that MSU cultures (used by labs to diagnose UTI) miss at least 50 percent of infections. Urinary dipsticks (used by GPs at the clinic to screen your sample) are even worse, and have been known for at least a decade to be completely unreliable in ruling out infection, missing up to 70 percent of infections. Ref <https://www.chronicutiaustralia.org.au/uti-testing/>

options, often citing guideline conservatism or antimicrobial-resistance concerns without engaging with the emerging evidence base or nuanced risk–benefit discussions.

As a result, [REDACTED] treatment is effectively being managed from overseas, while her local care in the ACT remains fragmented, conservative and largely unsupportive. This is not an acceptable situation for a resident of the national capital.

Medical misogyny, bias and consultation length (TOR 4)

[REDACTED] experience has been shaped by underlying gender bias and medical misogyny. Repeatedly, her pain and debilitating urinary symptoms were minimised, psychologised or attributed to stress rather than investigated thoroughly. She was told to “drink more water,” “relax,” or “live with it,” comments that would likely not be directed to a male patient with persistent urogenital pain and constant urinary symptoms.

Short consultation times in general practice compounded this bias. Chronic UTI and other pelvic pain conditions are complex, require detailed histories and sensitive discussion, and cannot be adequately addressed in a standard brief appointment. When doctors are under time pressure, it becomes even more likely that women’s symptoms are brushed aside in favour of quick, guideline-driven decisions that do not fit these complex presentations.

Economic, social and educational impacts (TOR 5 & 6)

Chronic UTI has severely affected [REDACTED] ability to work reliably, participate in family and community life, travel, and plan for the future. Frequent bathroom use, pain, sleep disruption and fatigue have contributed to lost work hours, reduced productivity and career stagnation. The ongoing costs of travel to interstate and overseas-aligned clinicians, private consultations, tests and medications (non PBS antibiotics) have also placed a significant financial burden on her household.

These individual impacts scale up to a substantial, but largely invisible, economic and social burden for the ACT when people with chronic pelvic and urogenital pain conditions cannot study, work or care for others to their full potential. Many of these impacts could be reduced if local clinicians were better educated, more open to evolving evidence, and supported to spend longer with complex patients.

Recommendations for the ACT (TOR 2, 3, 6 & 7)

Drawing on this experience, [REDACTED] urges the Committee to recommend that the ACT Government:

- Explicitly recognise chronic UTI and other under-diagnosed pelvic pain conditions as part of the inquiry’s scope and subsequent policy responses, noting that these may behave like “superbug” infections that are not adequately treated by standard short courses.
- Support longer, better-remunerated consultations in primary care and specialist clinics for complex pelvic and urogenital pain, so clinicians have time to listen, investigate and co-design care plans.
- Fund targeted education for GPs, urologists, gynaecologists, pain specialists and allied health professionals in Canberra on chronic UTI, endometriosis, adenomyosis, PCOS and other pelvic pain conditions, including up-to-date international approaches (such as those used by Professor Malone-Lee’s clinic) and balanced stewardship of long-term antibiotics.
- Establish or support multidisciplinary pelvic pain and urogenital pain services within the ACT that integrate gynaecology, urology, pain medicine, physiotherapy, psychology and, where appropriate, infectious diseases expertise.
- Facilitate ACT participation in national and international research collaborations and clinical trials on chronic pelvic pain and chronic UTI, so that local patients do not have to look overseas for evidence-based, innovative care.

[REDACTED] experience illustrates that when conditions like chronic UTI fall through the cracks of awareness, guidelines and service design, people are left in pain for years and must become their own advocates and researchers. The ACT has an opportunity through this inquiry to change that reality for future patients.

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