

Hearing Patient Voices Survey: Key Findings

The *Hearing Patient Voices* survey was conducted by Chronic UTI Australia (Inc.). The aim of the survey was to better understand the impacts of chronic UTI on individuals, as well as potential impacts on the health system and society in general. Four key themes emerged from the survey data:

1. Chronic UTI severely impacts quality-of-life.
2. Poor healthcare experiences are common among chronic UTI patients.
3. People with chronic UTI feel let down by diagnostic and treatment failures.
4. Health professionals' lack of knowledge and expertise in diagnosing and treating chronic UTI results in costs to the health system that could be avoided.

410 people completed the online *Hearing Patient Voices* survey in late 2021 and early 2022.

- 96.5% identified as female; 2.7% identified as male; and 0.7% identified as non-binary or gender diverse.
- The top five countries represented were Australia (40.2%), United Kingdom (28.3%), United States (14.3%), Canada (3.6%) and Ireland (2.7%).
- The age of participants ranged from 19 to 84 years, with a mean (average) of 46.7 years.
- Four in five participants had been diagnosed with a chronic UTI by a health professional at the time of the survey.

(More on demographics can be found on pages 12-13 of the full report.)

Nearly all experienced considerable pain (97.6%) and urinary frequency (91.5%) as their main chronic UTI symptoms.

- Other common chronic UTI symptoms reported included: cloudy, bloody or smelly urine (80.7%), bladder fullness (79.5%), overactive bladder (74.6%), voiding symptoms (72.7%); and stress urinary incontinence (42%).
- Nearly half of the respondents (47.8%) 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.'
- Self-reported symptoms triggers included sexual intercourse and other lifestyle factors (44.6%), inadequate acute UTI treatment (14.2%), surgical procedures (12.1%) and hormonal changes (9.2%).

(More on chronic UTI symptoms can be found on page 20 of the full report.)

More than 9 in 10 people said their overall quality-of-life had been impacted by their chronic UTI and nearly half described the impact as 'extreme'.

- Life domains most heavily impacted were the ability to have a happy sex life (83%); feeling good about yourself (77.1%); and maintaining good mental and emotional health (74.7%).
- Half of participants sampled had mental health component summary scores 'well below' the population norms and another 20% were 'below' the norm.
- 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 it.

(More on quality-of-life impacts can be found on pages 29 -30 and pages 42-43 of the full report.)

More than 80% of participants agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and can treat chronic UTI.

- Nearly 82% agreed or strongly agreed that their symptoms had been dismissed or not believed by a healthcare professional, with many expressing feelings of being ‘belittled’ or ‘disbelieved’ by a doctor.
- 92.7% had returned a negative urine culture test while experiencing UTI symptoms, yet only 39.5% had been told by a doctor about diagnostic inaccuracies with urinary dipsticks and urine cultures.
- Three in five participants had at a previous stage received an alternative diagnosis to explain their UTI symptoms (IC/PBS 55.1%; recurrent UTI 26.6%; mental health 17.3%; pelvic floor dysfunction 17.3%).
- More than two thirds of participants (67.1%) had been offered or given therapies they believed were inappropriate and/or ineffective; and about two thirds (64.4%) had been told nothing could be done for their symptoms.
- During their search for medical help, over half (51.7%) said they had experienced negative interactions with doctors, while a minority (13.9%) said they had experienced a health practitioner who had been nice/sympathetic/tried to be helpful.
- More than three quarters (76.8%) agreed or strongly agreed with the statement: ‘I have been given unhelpful advice to change my behaviour’ when seeking medical help for recurrent or persistent UTI symptoms.

(More on participants’ experiences seeking help for chronic UTI symptoms can be found on page 32-35 and page 44 of the full report.)

Survey participants had much higher health service utilisation than the general population, and this was most pronounced for resource intensive services.

- Survey participants were about three times more likely to be admitted to hospital or to have seen three or more health professionals in the previous 12 months.

(More on avoidable costs to the health system can be found on page 36 and 45 of the full report.)

Next steps

People with chronic UTI endure an enormous amount of unnecessary, preventable suffering. The *Hearing Patient Voices* survey showed that the distress of experiencing painful and life-altering physical symptoms is significantly compounded by a lack of understanding and mismanagement in the health system. Until now, the personal, financial and emotional impacts associated with this disease have been grossly underestimated and under reported. To stem this growing health problem, urgent collaboration between policy makers, health professionals, researchers and patient groups is needed to prioritise:

- education and resources (including new professional guidelines) for health professionals
- education of the public, especially high-risk groups such as young women
- specialist clinics dedicated to chronic and complex UTI presentations
- research funding to deliver reliable diagnostic methods and safer, faster effective treatments for UTI.

(More on the next steps can be found on page 46 of the full report.)