

Chronic UTI Australia Inc. survey results 2019

Key findings:

- More than a third of participants had experienced persistent UTI symptoms for 2-5 years, and more than half had experienced their symptoms for 6 years or greater.
- 92 percent of participants had experienced UTI symptoms while returning a negative urine culture.
- 85 percent of participants had experienced an improvement in their UTI symptoms after taking antibiotics, despite having a negative urine culture.
- Over a third of participants had seen their GP 6-10 times for symptoms relating to UTI in a single year.
- 71 percent and 33 percent of participants had been referred to a urologist or a urogynaecologist, respectively, for their persistent UTI symptoms. Urology being the most popular first choice referral for UTI.

Aim: To investigate how a population of people with persistent (intermittent or ongoing) urinary tract infection (UTI) symptoms are managing their condition in terms of tests and treatment.

Methods: An exploratory survey, called 'Chronic UTI Questions', was conducted in December 2019 using Survey Monkey. A link to the survey was posted in a number of online groups for people with persistent UTI symptoms. Participants were assured their data would be anonymous. Imelda Wilde from Chronic UTI Australia Inc. was the only person to collect and have access to the data.

Results: 340 people responded to the survey. Participants were primarily from Australia, the UK and the USA. The survey findings identified that a large proportion (92 per cent) of the participants had returned negative urine cultures while experiencing symptoms consistent with a urinary tract infection, with 85 per cent of those participants reporting that they had experienced symptom improvement after standard antibiotic treatment for their UTI symptoms, regardless of having returned a negative urine culture.

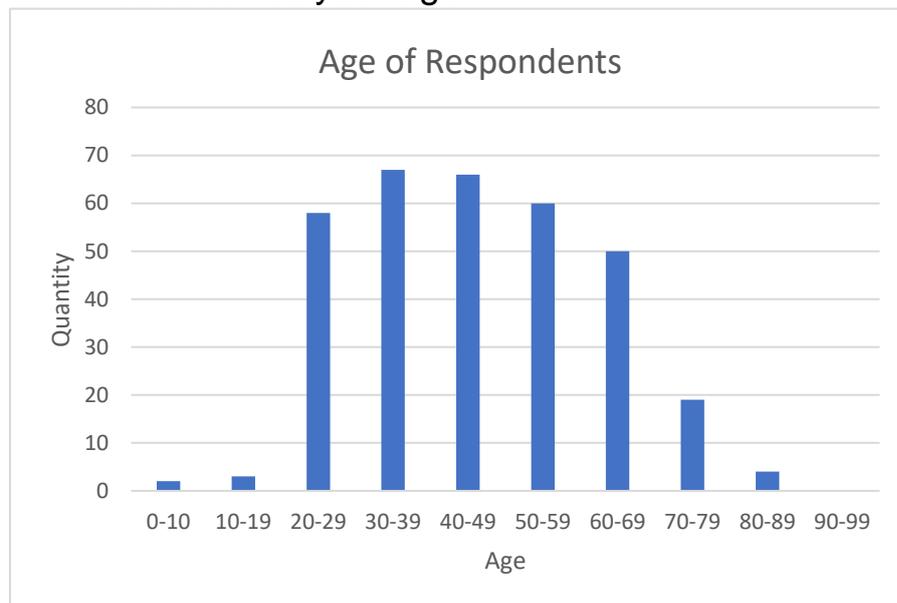
The survey findings also help us understand the high costs to individuals (due to repeated medical visits, associated expenses, and reduced quality of life), the health system (medical visits, diagnostic tests) and society in general (time off work/study, loss of productivity).

Discussion and conclusions: The results of this preliminary study are consistent with research evidence on the frequent failure of standard diagnostic tests to detect UTI.

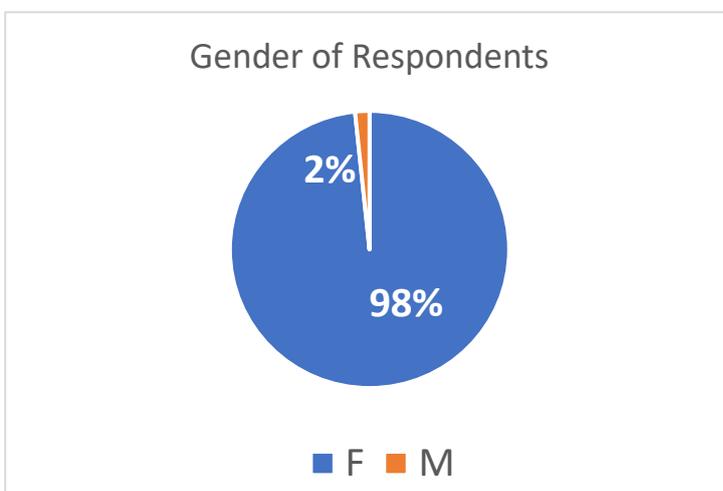
The survey findings are also consistent with the experience of patient advocacy groups, including Chronic UTI Australia Inc., that patients may experience intermittent or ongoing UTI symptoms for many years. Participants' frequent visits to GPs suggest they are not being adequately cared for in the primary health care setting. However, referrals to specialist urologists and other practitioners do not necessarily result in a resolution, and patients may be left with limited options once they have exhausted the usual processes. Our data suggest that the heavy reliance on culture tests to diagnose UTI is contributing to patients not receiving an accurate diagnosis and timely, appropriate care, leaving patients to self-manage a painful, lonely and difficult chronic illness.

Details of the survey results appear below.

Q1. Please tell us your age



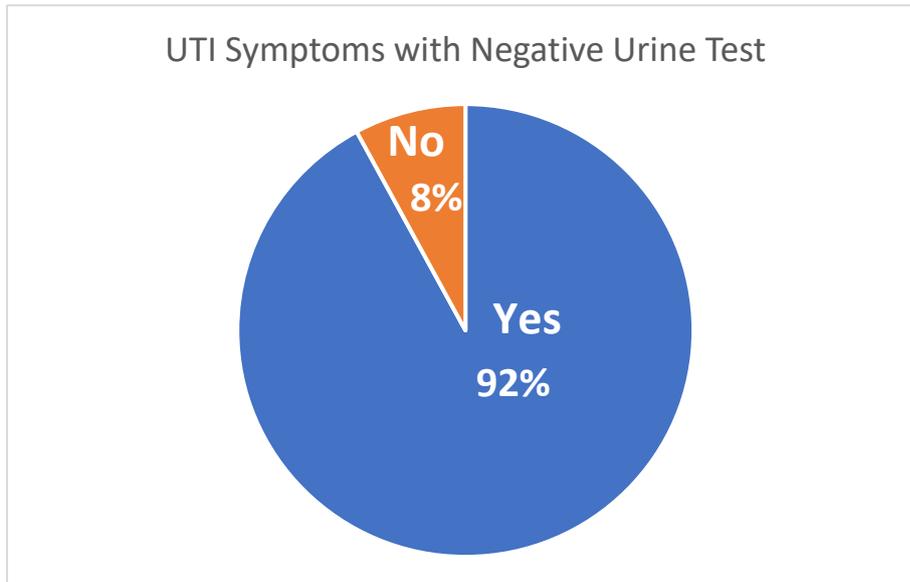
Q2. Please tell us your gender



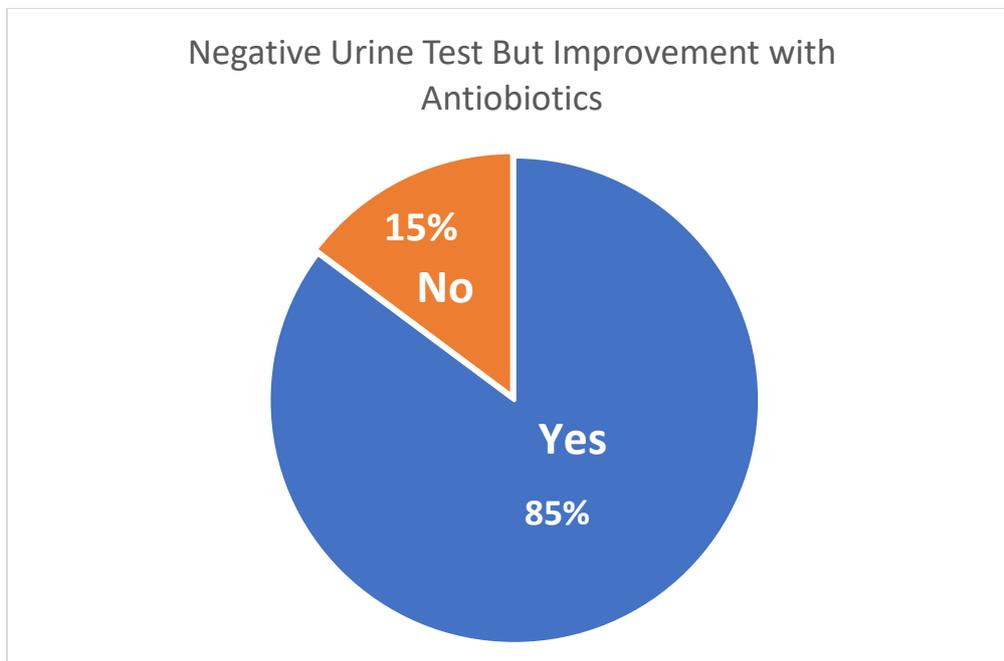
Note: This is likely not a true reflection of the population of men suffering UTI.

This is partly because men are often less likely to seek out help online, and also there are specific men's groups with thousands of members which we did not have access to at the time of the survey.

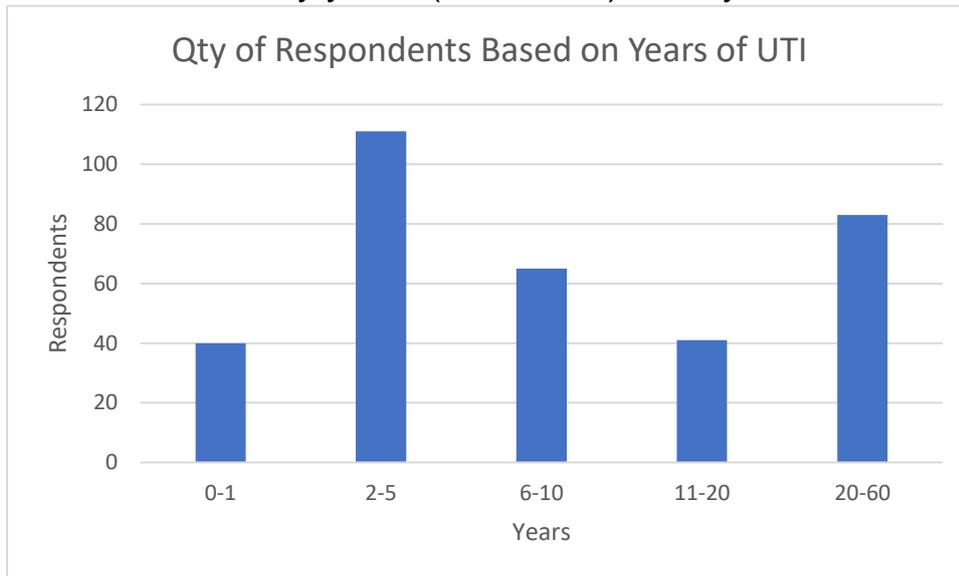
Q3. Have you ever experienced urinary tract infection (UTI) symptoms but had negative urine tests?



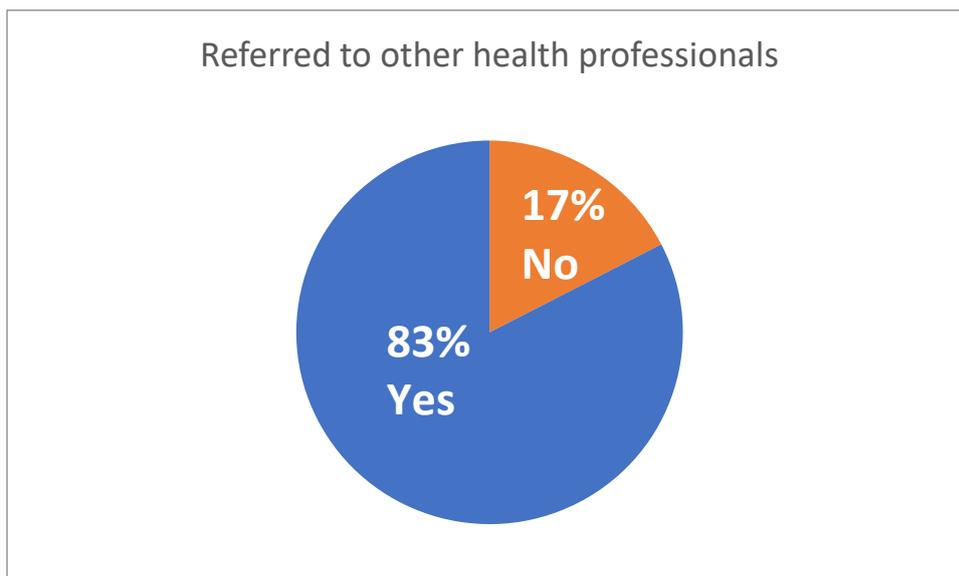
Q4. Have you ever had negative urine tests but improved UTI symptoms once taking antibiotics?



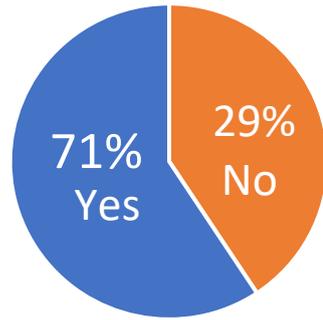
Q5. For how many years (or months) have you been suffering UTIs?



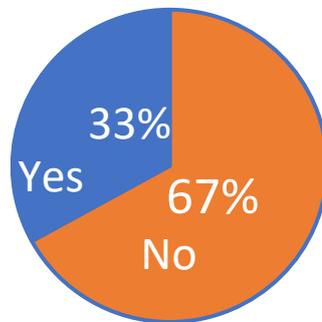
Q6. Have you been referred to other health professionals for your UTIs? Eg urologist, urogynaecologist, gynaecologist, pain specialist, microbiologist, infectious disease specialist, physiotherapist, psychologist, dietitian, other? Please write YES or NO and list the ones you have seen.



Percentage of respondents who have seen a Urologist

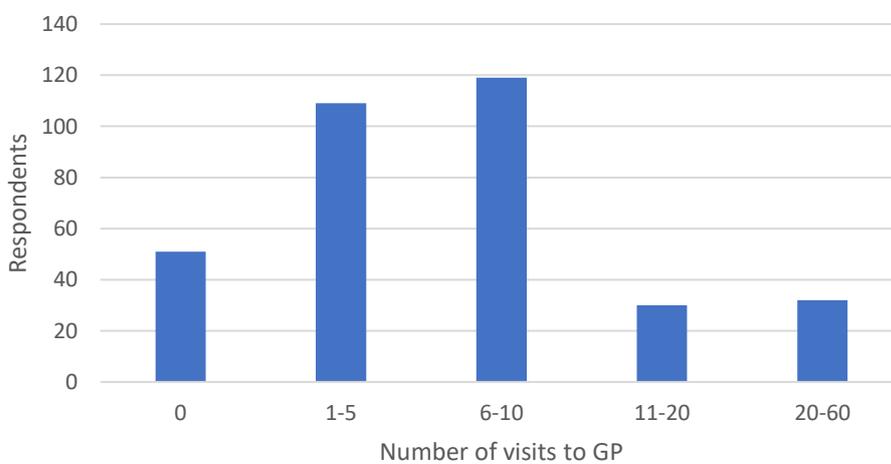


Percentage who have seen a Urogynaecologist

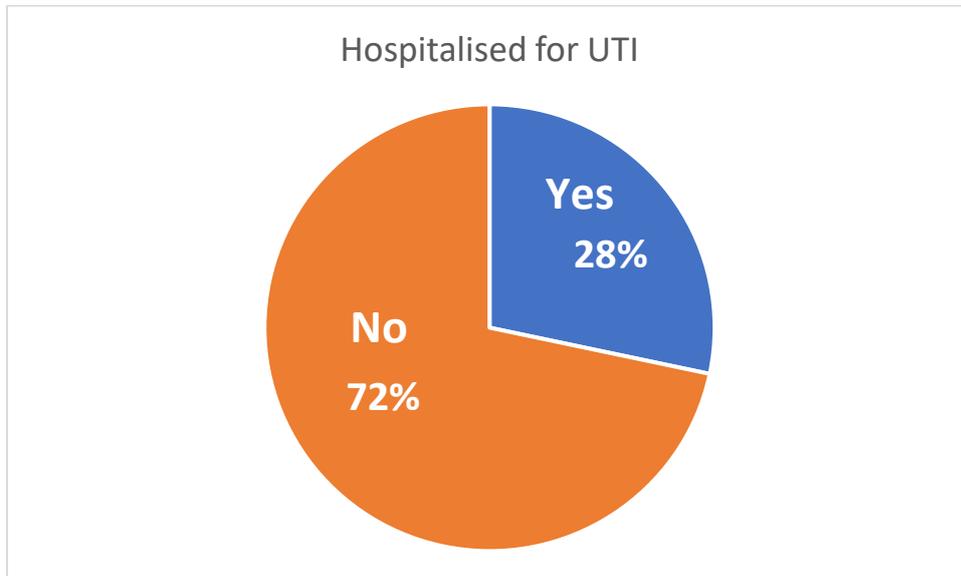


Q7. How many visits have you made to your GP in the past 12 months for anything relating to your urinary symptoms?

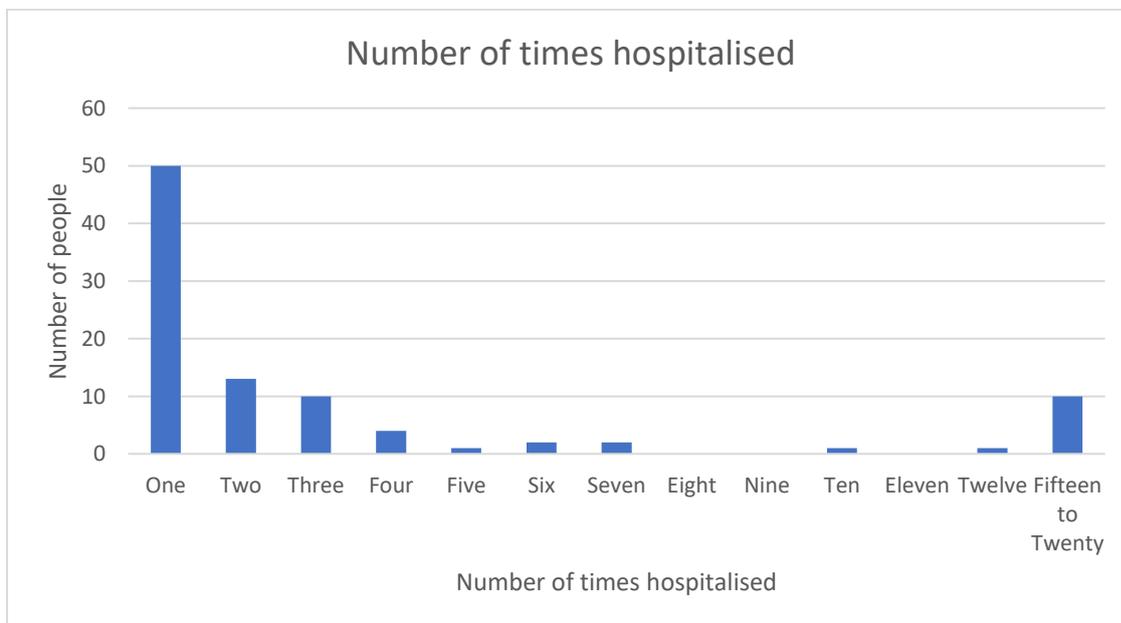
Number of GP Visits in the Last Year



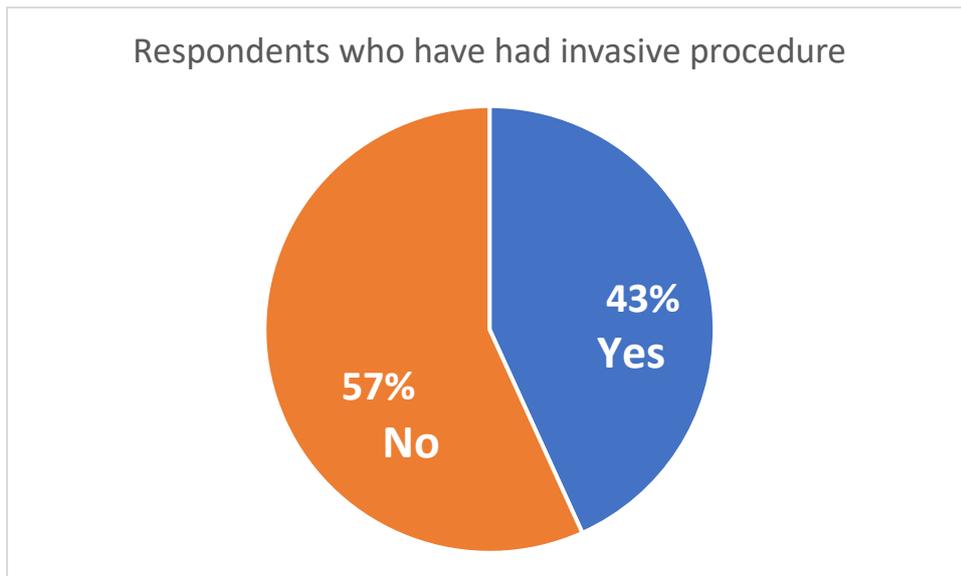
Q8. Have you ever been hospitalised because of a urinary tract infection?



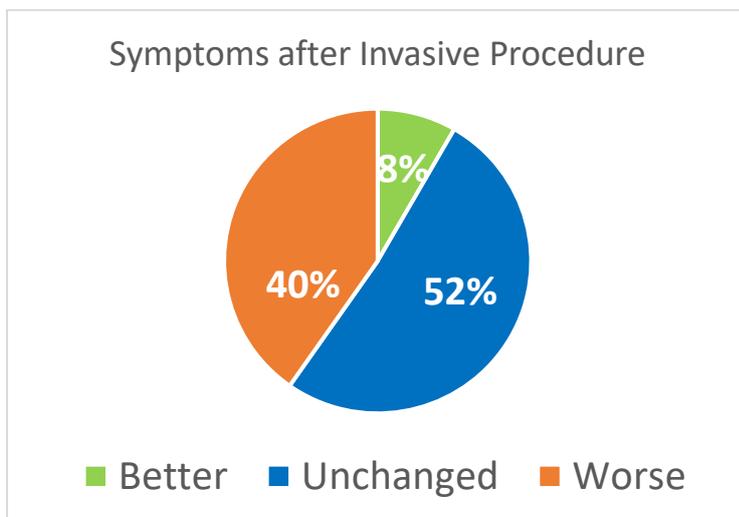
Q9. How many times have you been hospitalised?



Q10. Have you ever had an invasive procedure (eg dilatation, instillations) or surgery as a way to manage your urinary tract infections?



Q11. What was the effect of these invasive procedures/surgery on your UTI symptoms?



For the respondents to this survey, 92% are not better after invasive procedure