

Hearing Patient Voices:

CAPTURING
THE IMPACTS
OF CHRONIC
URINARY TRACT
INFECTION

Survey Report

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DEDICATION

We dedicate this report to the late Professor James-Malone Lee, who treated and researched lower urinary tract symptoms for 40 years. He was a highly intelligent and compassionate man who truly made a difference to people all over the world who suffer from chronic urinary tract infection (UTI). He, along with our patient community, is the inspiration behind the work described in the following pages.



ACKNOWLEDGEMENTS

Andrea Sherwin, Marilyn Clarke-Murphy and Imelda Wilde provided valuable input to the survey questionnaire and to the written report. The project has benefitted enormously from their deep understanding of the challenges experienced by people with chronic UTI.

We give thanks to the patient volunteers who pilot tested and provided feedback on the draft questionnaire.

We also acknowledge the volunteers around the world who manage online support groups and advocacy organisations for people suffering from chronic UTI. We are pleased that technology has enabled such groups and organisations, without which this growing patient group would remain isolated and unsupported. We are most appreciative of their support in promoting this survey to better understand the impacts of chronic UTI.

Finally, we are grateful to Community Underwriting for awarding us a grant to conduct the 'Hearing Patient Voices' survey, and to our corporate sponsors, Feel Better Box and Joode, for providing additional funds for the survey and for supporting the work of Chronic UTI Australia generally.

GLOSSARY

- A **urinary tract infection (UTI)**, also known as cystitis, bladder infection, water infection, kidney infection or pyelonephritis, is an infection occurring anywhere in the urinary tract—from the kidneys to the urethra. A lower UTI involves the bladder and anything below, like the urethra and prostate. An upper UTI involves the urinary system above the bladder, such as the ureters and kidneys (pyelonephritis).

- A **chronic UTI** is an embedded bacterial infection in the bladder and/or other part of the urinary tract. It is usually a result of an acute infection or series of infections that never fully went away. A chronic UTI can 'flare', which for some people feels like multiple separate acute infections. While some people feel symptom free between flares, others feel constant milder symptoms between flares. It is common for dipsticks and urine cultures to be interpreted as 'negative' with chronic UTI.

- People with more than two culture-positive UTIs in six months, or more than three culture-positive UTIs in one year, are generally diagnosed as having **recurrent UTI**.

- A **recalcitrant UTI** is a UTI which is difficult to treat effectively. This may be because the infection has become embedded in the bladder wall and/or because the pathogen causing the infection is resistant to the type of antibiotic used.

- People with ongoing or intermittent UTI symptoms and negative UTI test results are commonly diagnosed with a urinary syndrome, **such as interstitial cystitis/painful bladder syndrome (IC/PBS)**. IC/PBS has long been described as a 'diagnosis of exclusion'. This means it is a diagnosis that should be given when all possible causes of ongoing LUTS have been explored and excluded, including and most especially, infection. Research shows it is impossible to exclude infection under existing testing guidelines.

- **Lower urinary tract symptoms (LUTS)**. LUTS are a broad group of signs and symptoms that include the urgency, frequency, and incontinence of overactive bladder, voiding problems such as hesitancy and intermittency, stress incontinence, and pain, all variously overlapping.

- **Dipstick test**. Dipsticks are often the first diagnostic tool general practitioners (GPs) use to diagnose a urinary tract infection. These tests look for signs of infection, such as white blood cells (leucocytes or pus cells), blood, pH levels and nitrites.

- **Mid-stream urine (MSU) culture test and urinalysis**. This laboratory test uses quantitative microbial culture from a mid-stream urine sample to grow bacteria. The lab (either a real-life technician or an automated machine) will also conduct a urinalysis and look at a small amount of urine under a microscope to check for other signs of infection, such as white blood cells, red blood cells, epithelial cells, and any other signs. These readings will be used alongside the MSU culture results to determine if there is an infection.

SUMMARY

This report presents findings of ‘Hearing Patient Voices’, an online survey of 410 people with symptoms of chronic urinary tract infection (UTI). Participants were 396 women, 11 men and three non-binary/gender diverse people aged 19 – 84 years. Most lived in Australia (40.2%), the United Kingdom (28.3%) or the United States (14.3%), although many other countries were represented.

The aim of the ‘Hearing Patient Voices’ survey was to understand the impacts of chronic UTI on individuals, and the potential impacts on the health system and society in general. The importance of these issues is underscored by evidence, summarised in Chronic UTI Australia’s 2020-21 Annual Report (www.chronicutiaustralia.org.au/annual-reports), showing strong growth in hospitalisations related to UTI, and hence a growing burden to individuals and the health system.

Our participants were recruited mainly from online patient support groups. This is important to bear in mind when interpreting the survey findings, as participants were likely to have access to patient-focused information about chronic UTI that they could share with their doctors or use to find a knowledgeable health practitioner. Therefore, the rates of chronic UTI diagnosis and evidence-based treatment reported by our participants may be higher than among people experiencing chronic UTI symptoms who are not connected with patient support groups.

Four key themes emerged from the survey data: severe quality-of-life impacts; poor experiences of healthcare; diagnostic and treatment failures; and avoidable costs to the health system.

IMPACT OF CHRONIC UTI SYMPTOMS ON QUALITY-OF-LIFE

In contrast to the frequent characterisation of UTI as a trivial and easily treated condition, survey participants had suffered serious quality-of-life impacts from their chronic UTI symptoms, typically for years and sometimes for decades.

Chronic UTI can be an extremely painful and debilitating condition. Nearly all (97.6%) of our sample reported pain as one of their chronic UTI symptoms. Approximately 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.’ One participant commented:

“The 10 in pain is not an exaggeration...it was hell I’ve never felt before nor anything near since.”

More than 90% of participants also struggled with urinary frequency. This could be so severe that it kept people housebound and unable to sleep.

When asked to rate the effect of chronic UTI on their lives ‘overall’, most participants (93.7%) indicated at least a moderate impact. 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’. For all life domains except ‘managing finances’, a majority of participants (more than 50%) rated the impact of chronic UTI symptoms as at least ‘moderate’.

The figure on the next page lists the key themes that emerged when participants were asked to explain in their own words how their lives had been affected by chronic UTI symptoms, along with examples of participants’ comments. The figure shows that 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.



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. Analysing scores on the Short Form-12, version 2 (SF-12v2®), a 12-item questionnaire about people’s health and wellbeing, we found that half of our sample had mental health component summary scores ‘well below’ the population norms and another 20% were ‘below’ the norm.

Although we were aware of these impacts before conducting the survey, it was difficult to read the countless harrowing descriptions of how participants’ lives had been derailed by extreme pain, urinary frequency and other debilitating symptoms. In the worst cases, participants were housebound, had lost their livelihoods and close relationships, and saw little hope for the future.

Survey findings relating to participants’ quality-of-life are presented in **Section 4.2** and discussed further in **Section 5.2**.

EXPERIENCES OF SEEKING MEDICAL HELP

The distress caused by chronic UTI symptoms is often compounded by health professionals’ lack of understanding and ability to diagnose and treat the condition. Further, the survey findings included many accounts of patients being poorly treated in the health system. Some participants did report being treated with kindness, respect and understanding, but they were very much in the minority.

Most participants (82.6%) agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and can treat chronic UTI. A high proportion (81.9%) also agreed or strongly agreed that their symptoms had been dismissed or not believed by a healthcare professional. Many reported feeling ‘belittled’ and ‘disbelieved’ by professionals from whom they sought help.

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, consume cranberry products, 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.’

Due to the proven deficiencies of UTI tests (noted below and detailed in the report) and poor understanding of chronic UTI among health professionals, almost two thirds of participants (62.2%) had received alternative diagnoses to explain their symptoms. The most common alternative diagnoses, reported by 55.1% of participants, were 'interstitial cystitis' (IC) or 'painful bladder syndrome' (PBS). Most concerning, 17.3% had received a mental health 'diagnosis' to explain their symptoms. As we discuss in this 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.

Overall, about four in five participants had been diagnosed with chronic UTI by a health practitioner at the time they completed the survey. The other participants suspected they had a chronic UTI, based on their symptoms. The relatively high rates of chronic UTI diagnosis among our participants may reflect the fact that they had access to chronic UTI-informed doctors, as a result of information shared in online support groups. Our participants frequently commented on the difficulty they had obtaining a diagnosis before they had access to this information.

The survey findings suggested that getting a diagnosis of chronic UTI may be more difficult in Australia than many other countries. Only 72.8% of our Australian participants had been diagnosed by a health professional, compared with 83.7% of international residents. Further, 27 of the 120 Australians who had been diagnosed by a health professional had received their diagnosis overseas. Several participants commented on the high cost of accessing treatment from specialist clinics overseas and/or the long waiting times to access these overburdened services.

At the time of the survey, almost half of all participants (49.0%) said they had access to a healthcare professional who understands chronic UTI. While it is concerning that half did not have such access, even more concerning is the fact that our participants are likely to have had better access to evidence-based information and treatment than others in the community not connected with online patient groups.

Survey findings relating to participants' experiences of seeking help for chronic UTI symptoms are presented in [Section 4.4](#) and discussed further in [Section 5.3](#).

TESTING AND TREATMENT FAILURES

Most survey participants felt let down by tests used by medical practitioners to diagnose their condition. In [Section 5](#) of this report, we cite some of the extensive scientific evidence on the inaccuracy of routinely used UTI tests. Consistent with this evidence, 92.7% of participants had returned a negative urine culture test while experiencing UTI symptoms. This often meant they were denied antibiotic treatment despite having clinical symptoms and a personal history consistent with UTI. The following quotes are typical:

"[I've] been told it was all in my head as I returned a negative test result."

"[I was portrayed as] someone who may be addicted to pain medication claiming to be in excruciating pain despite having negative UTI results."

"I...would not be given antibiotics without an infection showing in urine so I was diagnosed with Interstitial Cystitis."

Many participants reported that health professionals' frequent lack of understanding that UTI tests can be inaccurate, and lack of awareness of chronic UTI, had led to misdiagnosis and ineffective, potentially harmful, medical, and surgical treatments. More than two thirds of participants (67.1%) had been offered or given therapies they believed were inappropriate and/or unhelpful. These were not only ineffective in most cases, but could be invasive, have unpleasant and sometimes irreversible and harmful side effects, cause pain, exacerbate symptoms, and be expensive.

While about two thirds (64.4%) of our participants had been told by a healthcare professional that nothing could be done for their symptoms, the scientific literature contains evidence that chronic, embedded infections can be cleared through the continuous use of full-strength antibiotics – often for a protracted period. In our survey, participants undergoing this form of treatment were significantly more likely than others to report that their chronic UTI symptoms were improving.

Despite chronic UTI being a treatable – albeit challenging – condition, the survey findings demonstrate the difficulties of accessing effective treatment. Participants who received antibiotics often did so only intermittently or at low (prophylactic) doses. 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.

The survey highlights the need for appropriate diagnosis and treatment of acute and recurrent UTI, with the expectation that this will reduce the risk of infections becoming embedded and chronic. Several participants expressed a view that too short and/or intermittent courses of antibiotics had contributed to the development of their chronic UTI.

Although a few participants appeared to have developed chronic UTI after a single infection, on average there was 8.5 years between participants' first UTI and the onset of persistent symptoms indicating a chronic UTI.

There is, therefore, potentially a substantial window for proper treatment and prevention of acute and recurrent UTI, which may help reduce the risk of symptoms becoming persistent or chronic.

Once an infection has become chronic and embedded, it is essential that the person is able to access evidenced based, sustained and

affordable treatment. In our survey, many participants commented on the difficulty of getting access to the protracted antibiotic treatment their infections required, often because their doctor admitted to being worried about falling foul of policies designed to limit antibiotic prescribing.

While strongly endorsing patient access to the most effective chronic UTI treatment currently available, Chronic UTI Australia also advocates for urgently needed research to develop better alternatives. We note that several survey participants expressed concern about having to take long-term antibiotics, with some mentioning physical health problems, such as digestive issues, they believed had been caused or exacerbated by antibiotics.

Survey findings relating to diagnosis and treatment of UTI are presented in [Section 4.1](#) and discussed further in [Section 5.1](#).

COSTS TO THE HEALTH CARE SYSTEM

Chronic UTI is causing avoidable costs to the health care system. Comparison of our participants 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 were not suitable for gauging the extent of health costs due to chronic UTI, the results suggest a high level of potentially avoidable expenditure.

Survey findings relating to participants' use of health services are presented in [Section 4.5](#) and discussed further in [Section 5.4](#).

CONCLUSION

Chronic UTI is one of several health conditions predominantly affecting women that are traditionally neglected in medical research and practice. While conditions such as endometriosis and pelvic mesh injury are finally getting the attention they deserve, chronic UTI remains poorly recognised and treated.

Chronic UTI is a significant women's health condition and an under recognised and under diagnosed cause of persistent pelvic pain.

Sufferers of chronic UTI are more likely to access resource intensive medical services such as specialists and hospitalisations, and receive misdiagnoses, unnecessary invasive tests and inappropriate treatments.


People with chronic UTI endure distressing life altering symptoms that can persist for many years, even decades. Collectively, they describe harrowing experiences of unacceptably poor treatment within the health system and feelings of neglect, being dismissed, belittled or not believed by health professionals.

Most people surveyed had mental health and wellbeing scores below those of the general population, and of great concern, one in ten disclosed having suicidal thoughts.

The apparent lack of chronic UTI knowledge among healthcare providers has led to many sufferers being forced to seek a diagnosis and treatment from specialist clinics abroad.

Through this patient survey, Chronic UTI Australia is raising critical awareness of this neglected health condition and the detrimental impact it has on those who suffer, mostly in silence.

To turn the tide, education is needed among healthcare professionals and the public—especially high-risk groups such as young women. We must ensure there is communication and positive engagement between patient groups, health professionals, researchers and policy makers. Dedicated chronic UTI specialists must be introduced to pelvic pain clinics Australia-wide, and significant funding for applied and translational UTI research must be given the highest priority to stem this growing public health problem.



Most people surveyed had mental health and wellbeing scores below those of the general population, and of great concern, one in ten disclosed having suicidal thoughts.

INTRODUCTION

Chronic UTI Australia (Incorporated) is a volunteer-run national patient organisation advocating for:

- Better testing, diagnosis, and treatment of all forms of urinary tract infection (UTI)
- Awareness that people are developing chronic, embedded bladder infections due to current testing and treatment failures.

We conducted a preliminary survey of our patient community in December 2019, attracting 340 responses. The results of that preliminary research were used to help design the 'Hearing Patient Voices' survey, which is the subject of this report.

We were fortunate to be awarded a grant from Community Underwriting (www.communityunderwriting.com.au). This enabled us to commission a professional survey research company, Websurvey (www.websurvey.com.au), to help with the survey's development and host it on secure online portals.

The aim of the 'Hearing Patient Voices' survey was to understand the impacts of chronic UTI on individuals, and the potential impacts on the health system (for example, because of medical visits, diagnostic tests, surgical procedures and UTI related hospital admissions) and society in general (loss of productivity).

This report describes how we developed and implemented the survey, presents its key findings, and discusses the results in terms of their implications for health policy, clinical practice and research.



METHODS

2.1 SURVEY DEVELOPMENT

Chronic UTI Australia developed a draft questionnaire designed to capture the quality-of-life impacts of chronic UTI and the potential flow-on effects to the health system.

The questionnaire included a validated tool for measuring health-related quality-of-life. After researching available tools, we obtained a licence from QualityMetric (www.qualitymetric.com) to use the Short Form-12, version 2 (SF-12v2®), a 12-item questionnaire that asks about respondents' perceptions of their health and wellbeing.

The survey also contained pre-coded questions about the person (their age, gender, place of residence etc); their UTI history and symptoms; use of health services; and both pre-coded and open-ended (free text) questions about the impact of their chronic UTI symptoms on various life domains.

The draft questionnaire was refined after being pilot tested with five chronic UTI patients and receiving feedback from Websurvey's survey design experts. Websurvey then formatted the questionnaire as an interactive online survey.

2.2 ELIGIBILITY CRITERIA

The survey was open to:

- people aged 16 and over who have been diagnosed by a health professional as having a chronic UTI or who suspect they have a chronic UTI based on ongoing or recurrent UTI symptoms.
- people who are parents or carers of children aged under 16 who have been diagnosed by a health professional as having a chronic UTI or who are suspected to have a chronic UTI based on ongoing or recurrent UTI symptoms.

While it was expected that many participants would come from Australia, we actively recruited from international patient advocacy and support networks and welcomed participation from residents of overseas' countries. However, the survey was limited to people who speak English.

2.3 PARTICIPATION IN THE SURVEY

Chronic UTI Australia invested considerable effort in recruiting survey participants. We hoped that a larger sample would improve the credibility of the survey with policy makers, health professionals and researchers – the people with the power to improve UTI diagnostic testing and treatments. Participants were recruited via online support groups and social media platforms used by people with recurrent and chronic UTI and from the networks developed by Chronic UTI Australia since it was established in 2018.

The survey was launched in late September 2021 and was taken offline in January 2022, after it had been completed by 410 people.

Before beginning the survey, participants read an information statement to help them decide if they were eligible to participate in the survey and whether they wished to do so. The information statement is in **Attachment 1**.

We encouraged participants to set aside about half an hour to complete the survey. However, the time each participant needed to complete the questionnaire depended on the level of detail provided in response to the free-text questions. If the survey could not be completed in one go, participants were able to save their responses and return later to complete the survey.

Participants could opt not to answer any question or reply to free text questions as briefly or as fully as they chose. Many gave detailed answers to several optional free-text questions, resulting in a rich source of data for our analysis.

Websurvey, the company we commissioned to host the survey, was asked to fully protect participants' confidentiality. When providing Chronic UTI Australia with data from the survey, Websurvey did not link the completed questionnaires to email addresses, so the identity of the respondent was not known to us unless the respondent chose to provide this information on the questionnaire.

Most results of the survey are reported as group data only, and participants' individual information is not identifiable in this report. Where individual responses are quoted in the report, we have removed any references that could allow people to guess their identity.

ABOUT THE PARTICIPANTS

All except one of the 410 people who completed the survey answered the questions on their own behalf. One participant was a parent of someone with a chronic UTI and answered the questions about their child. Examination of this survey record showed that this participant’s child was a teenager aged over 16 years.

3.1 GENDER

The sample was heavily weighted towards women: 396 participants (96.5%) identified as female; 11 (2.7%) identified as male; and the remaining three participants (0.7%) identified as non-binary or gender diverse. This result undoubtedly reflects the fact that UTIs affect women more frequently than men, and most chronic UTI patients are women. Further, members of online patient support groups – which were the main source of recruitment to the survey – are more likely to be female,¹² as are respondents to online surveys.³



3.2 AGE AND STAGE OF LIFE

The age of the participants ranged from 19 to 84 years, with a mean (average) age of 46.7 years. [Table 1](#) shows the distribution of ages across various categories.

Female participants were asked about their stage of reproductive life, with the results broadly reflecting the age distribution of the sample. There were no pre-pubescent participants. About half (49.0%) of the female participants were of reproductive age; one in ten (10.2%) were perimenopausal or menopausal; and just over a third (36.3%) were post-menopausal. Five respondents either did not know their reproductive stage of life or chose not to divulge it.

3.3 COUNTRY OF RESIDENCE

As shown in [Figure 1](#), Australia was the participants’ most common country of residence: 165 (40.2%) of participants lived in Australia at the time of completing the survey. The next most common countries of residence were the United Kingdom (28.3%) and the United States (14.3%), although many other countries were represented.

Table 1:
Participants’ age categories

Age range (years)	Number of participants	% of sample
18-24	22	5.4
25-34	94	22.9
35-44	81	19.8
45-54	74	18.0
55-64	77	18.8
65-74	45	11.0
75+	17	4.1
Total	410	100.0

3.4 MINORITY GROUPS

Table 2 shows the number and percentage of participants who identified as Aboriginal Australian or Torres Strait Islander; a person living with a permanent disability; and/or lesbian, gay, bisexual, transsexual, queer, intersex, asexual (LGBTQIA).

Aboriginal Australian and Torres Strait Islander people and those with a permanent disability appeared to be somewhat under-represented in our sample, compared with their estimated proportion of the population. According to the Australian Bureau of Statistics (ABS), there were 798,400 indigenous people in Australia in 2016 or 3.3% of the total Australian population at that time.⁴ The World Health Organisation estimates that about 15% of the world’s population lives with some form of disability, of whom 2–4% experience significant difficulties in functioning.⁵

The proportion of LGBTQIA people in our sample appeared roughly consistent with population estimates. In international and Australian research, 3–4% of the population have reported identifying as gay, lesbian or bisexual. This figure is higher among people younger than 25 in Australia – rising to 4% for male participants and around 7% for female.⁶

The under-representation of certain minority groups among our participants is consistent with research evidence that disadvantaged and marginalised communities are less likely to participate in online patient support groups,⁷ which was the main source of recruitment to our survey. As discussed in **Section 5**, Chronic UTI Australia is concerned about the impact of chronic UTI on disadvantaged groups such as Aboriginal peoples, the elderly and people with disabilities. These groups may be both more likely to experience UTIs and less likely to access accurate information, support and appropriate treatment.

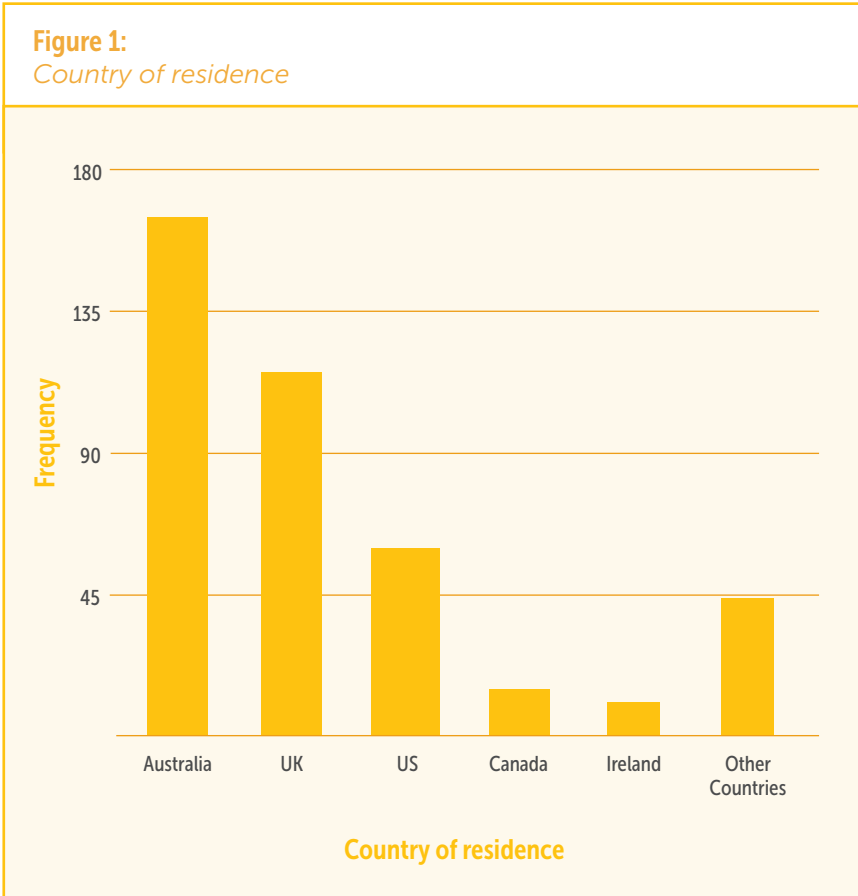


Table 2:
Participants identifying as belonging to selected minority groups

	Aboriginal Australian or Torres Strait Islander	Lesbian, gay, bisexual, transsexual, queer, intersex, asexual	Person with a permanent disability
Number of participants	3	18	45
Percentage of participants (n = 410)	0.7%	4.4%	11.0%

3.5 OTHER HEALTH CONDITIONS

Just over half the participants (226 or 55.1%) had at least one other health condition besides chronic UTI symptoms. As would be expected, older participants were more likely to report other health problems.

Participants could list up to five other health conditions. They mentioned many specific conditions, which were coded into the categories shown in [Table 3](#). Due to the possibility that respondents could have reported two or more specific conditions from within the same category, the results are reported as the ‘number of times mentioned’ rather as the number of participants.

Of the ‘other health conditions’ mentioned, in about half of cases the participant reported that the condition had started before the onset of their chronic UTI symptoms (see [Table 4](#)). While the data are unsuitable for attributing a causal relationship between health conditions and the development of chronic UTI symptoms, answers to later survey questions – such as our question on perceived triggers for chronic UTI symptoms ([Section 4.1](#)) – indicated that some participants had conditions that had predisposed them to developing UTIs, and hence to an increased risk of chronic UTI symptoms. Such conditions included compromised immune function (for example, due to autoimmune conditions, cancer treatments, or organ transplants) or conditions leading to surgical injuries (such as prolapse surgery using pelvic mesh).

Table 3:
Number of times ‘other health conditions’ were mentioned by participants

Health condition (coded)	Number of times mentioned
Mental health or behavioural problem	116
Gynaecological condition, including vaginal and vulval problems	113
Disorders of the digestive tract	76
Musculoskeletal disorders	63
Neurological condition, including headaches and migraines and diseases affecting the nerves	56
Hormonal/endocrine condition, including diabetes	51
Cardiac/vascular condition, including high/low blood pressure	46
Autoimmune or inflammatory disease not otherwise specified	40
Fibromyalgia/ME/chronic fatigue syndrome	34
Asthma/pulmonary disease	26
Cancer	11
Other	56

These participants were very much in the minority, with most conditions listed by participants appearing unlikely to have caused UTIs. In fact, many participants commented later in the survey that they had been healthy and active before the onset of their chronic UTI symptoms.

Several participants mentioned in answer to later survey questions that they had experienced serious physical health complications, such as kidney infection, sepsis, and pregnancy loss, due to untreated or poorly treated UTI. Further, a small number of participants mentioned physical health problems that they believed had been caused or exacerbated by chronic UTI treatment, usually antibiotics. These included digestive problems, tinnitus, and vertigo.

However, many of the ‘other health conditions’ reported as occurring after the development of chronic UTI symptoms appeared unlikely to have been directly caused by chronic UTI. The clear exception was ‘mental health conditions’, which were reported by 116 participants overall (28.3% of the sample). As discussed in [Section 4.3](#), responses to later survey questions indicated that many participants had developed problems such as anxiety and depression as a direct consequence of their chronic UTI symptoms. As we discuss in [Section 4.4](#), the distress caused by chronic UTI symptoms is often compounded by medical professionals’ lack of understanding and knowledge in diagnosing and treating their condition.

A final noteworthy feature of the survey data on participants’ ‘other health conditions’ is the high proportion (29.0%) of participants reporting gynaecological conditions such as endometriosis and vulvodynia. In contrast, a recent Australian study found that 6% of women had clinically confirmed endometriosis by age 40–44 years: this increased to 11.4% when adding diagnoses of clinically suspected endometriosis.⁸ Our survey findings are consistent with our impression, from interactions with our patient community, that chronic UTI patients do seem to experience gynaecological conditions at higher rates than would be expected. We do not have an explanation for this finding.

Table 4:

Conditions developing before and after the onset of chronic UTI

When condition started	First condition listed	Second condition listed	Third condition listed	Fourth condition listed	Fifth condition listed
Condition developed before onset chronic UTI symptoms	124 (54.9%)	57 (49.6%)	35 (52.2%)	11 (39.3%)	8 (66.7%)
Condition developed since participant started experiencing symptoms of chronic UTI	65 (28.7%)	44 (38.2%)	26 (38.8%)	13 (46.4%)	4 (33.3%)
Participant unsure if this condition started before or after symptoms of chronic UTI	37 (16.4%)	14 (12.2%)	6 (8.9%)	4 (14.3%)	-
Total	226 (100%)	115 (100%)	67 (100%)	28 (100%)	12 (100%)

FINDINGS

4.1 UTI DIAGNOSIS, HISTORY, AND SYMPTOMS

Diagnosis

Table 5 shows that nearly 80% (79.3%) of participants had been diagnosed with chronic UTI by a health professional, either in Australia or overseas. However, there was a significant difference between Australian residents and those living in other countries in whether they had received a diagnosis from a health professional. Overall, 72.8% of Australian residents had been diagnosed by a health professional, compared with 83.7% of international participants.

Table 5:
Health professional diagnosis of chronic UTI in Australia versus other countries

	Australia	All other countries	Total
I have/had a chronic UTI diagnosed by a health professional in Australia	93 (56.4%)	1 (0.4%)	94 (22.9%)
I have/had a chronic UTI diagnosed by a health professional overseas	27 (16.4%)	204 (83.3%)	231 (56.3%)
Total diagnosed by a health professional	120 (72.8%)	205 (83.7%)	325 (79.3%)
I have not been diagnosed by a health professional, but I think I have/have had a chronic UTI	40 (24.2%)	36 (14.7%)	76 (18.5%)
Other	5 (3.0%)	4 (1.6%)	9 (2.2%)
Total	165 (100%)	245 (100%)	410 (100%)

Further, 27 of the 120 Australians who had been diagnosed by a health professional had received their diagnosis overseas. A chi-squared analysis of the data presented in Table 5 showed that the probability of these results occurring by chance is less than 0.001%.

The importance of these findings, and the difficulties of being correctly diagnosed with chronic UTI in Australia, are discussed in Section 5.

Consistent with the results of our previous survey, over 90% of participants had returned a negative urine culture test while experiencing UTI symptoms (see Table 6). This result supports the extensive scientific evidence on the inaccuracy of recommended diagnostic tests for UTI. Selected peer-reviewed articles on this subject are noted in Section 5.



Other diagnoses to explain lower urinary tract symptoms

Table 6:
Experiences of UTI symptoms while returning a negative culture

Answers to question "Have you ever experienced UTI symptoms while returning a negative urine culture?"	Number (%) of participants
Yes	380 (92.7%)
No	23 (5.6%)
Don't know	7 (1.7%)
Total	410 (100%)

"I even went across the country to see a pelvic health specialist...and she told me I have IC and to keep going with PT [physical therapy], nerve blocks and bladder botox even though they weren't helping."

"In 2019 one specialist urologist...described my constantly looking for answers to get well as 'You must know you are an extremely anxious person'."

"I also received...comments with regards to constipation, he claimed this could be causing my symptoms."

"Vaginitis due to [being] post menopause and a 'this can happen' approach in older women, although they knew I'd had this condition since my 20s."



Related to the difficulties of diagnosing chronic UTI, participants had received a range of alternative diagnoses to explain their lower urinary tract symptoms (LUTS). Overall, 255 participants (62.2%) had received an alternative diagnosis. [Table 7](#) shows the number of participants reporting various alternative diagnoses.

Table 7: <i>Alternative diagnoses</i>	
Diagnosis	Number (%) of participants reporting having received an alternative diagnosis as an explanation for lower urinary tract symptoms (LUTS)
Bladder/urinary disorder (e.g., interstitial cystitis, bladder pain syndrome)	226 (55.1%)
Recurrent UTI	109 (26.6%)
A mental health diagnosis	71 (17.3%)
Pelvic floor tightness or dysfunction	71 (17.3%)
Vulvodynia	32 (7.8%)
Endometriosis or other conditions affecting the female reproductive system	29 (7.0%)
An autoimmune condition	10 (2.4%)
Prostatitis/epididymitis	2 (0.5%)
Other (e.g., imagination, structural abnormality, Fowler’s syndrome, prolapse, nerve damage, thrush, heavy metal or mould toxicity, vaginitis, lack of oestrogen, sexually transmitted infection)	26 (6.3%)

The diagnoses listed in [Table 7](#) are not necessarily inaccurate. As discussed in [Section 3.5](#), people can experience other health conditions alongside chronic UTI – many of which may be unrelated to or distinct from their chronic infection. However, when health professionals dismiss chronic UTI symptoms as being part of another condition, they deny the patient the opportunity for accurate diagnosis and appropriate treatment for the underlying cause of the symptoms – chronic infection.

Of specific concern in relation to the findings reported in [Table 7](#) is the large number of participants reporting that their lower urinary tract symptoms (LUTS) had been attributed to a mental health condition (such as stress and/or anxiety) or dismissed as being “all in your head.” This is a form of medical gaslighting, as discussed in [Section 5](#).

[Section 5](#) also outlines our concerns with diagnoses such as interstitial cystitis and bladder pain syndrome (IC/PBS). These are diagnoses of exclusion, and their application when an infection has not been excluded – due to faulty diagnostic tests – is inappropriate.

History

Table 8 shows responses to survey questions asking how long it had been since participants had experienced (a) their first acute UTI and (b) persistent UTI symptoms. The results indicate that most participants – nearly 90% in both cases – had a long history of acute and chronic UTI symptoms.

Although chronic UTI typically forms after a person has had one or more acute infections, 20 participants believed they had never had an acute UTI or did not know if or when they had experienced an acute UTI. Due to the now well-established inaccuracy of UTI testing, as evidenced in Section 5.1, some people without a previous UTI history and unfamiliar with the symptoms might not know they had a UTI if a medical professional had ruled out infection based on a negative test.

Table 8:
Time since first UTI and the onset of persistent symptoms

	Time since first acute UTI	Time since persistent UTI symptoms
Less than one year	34 (8.3%)	40 (9.8%)
One year or more	356 (86.8%)	365 (89.0%)
Never had an acute UTI	12 (2.9%)	-
Don't know	8 (2.0%)	5 (1.2%)
Total	410 (100%)	410 (100%)

Participants who had experienced their first acute UTI a year or more ago, and those who had suffered chronic UTI symptoms for a year or more, were asked how long it had been since the onset of their first acute infection or chronic symptoms, respectively. The time since participants' first UTI ranged from one to 60 years, with a mean (average) of 17.5 years. The period since the onset of chronic UTI symptoms ranged from one to 55 years, with an average of 9.0 years.

These results suggest that there is an average period of 8.5 years between a first UTI and the onset of persistent symptoms indicating a chronic UTI. There is, therefore, potentially a substantial window for proper treatment and prevention of acute UTI. As discussed in Section 5, this survey result highlights the need for appropriate diagnosis and treatment of acute and recurrent UTI, with the expectation that this will reduce the risk of infections becoming embedded and chronic.

Symptoms

Participants were given a list of common chronic UTI symptoms and asked to indicate symptoms they had experienced that they believe to be related to their chronic UTI. The results are shown in [Table 9](#).

Table 9:

Symptoms that participants believed to be related to chronic UTI

Symptom	Number (%) of participants reporting symptoms
Pain	400 (97.6%)
Urinating more frequently than normal	375 (91.5%)
Cloudy, bloody or smelly urine	331 (80.7%)
A feeling that the bladder is still full after urinating	326 (79.5%)
Overactive bladder symptoms	306 (74.6%)
Voiding symptoms	298 (72.7%)
Stress urinary incontinence	172 (42.0%)
Other (e.g., burning, urinary urgency, nausea, malaise)	170 (41.5%)



While not everyone experienced the same symptoms, many symptoms were experienced by a high proportion of participants. Pain, for example, was almost universal: 97.6% of our sample reported this symptom. Most participants also struggled with urinary frequency.

When later asked to describe the impact of their chronic UTI symptoms (see **Section 4.3**), the responses indicated that some people struggled most with urinary frequency – which could be so severe that it kept people housebound and unable to sleep – while others were more debilitated by pain.

Ratings of pain severity

“The 10 in pain is not an exaggeration...it was hell I’ve never felt before nor anything near since.”

Table 10 shows the results of our survey question asking people to rate the worst pain they had experienced from their chronic UTI symptoms since their persistent (intermittent or ongoing) UTI symptoms began. This question was asked only of those participants who reported pain as a symptom.

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.’

Table 10:
Table 10: Ratings of pain associated with chronic UTI symptoms

Pain rating	Frequency	Percent
1 - Very mild	1	.3
2 - Discomforting	4	1.0
3 - Tolerable	2	.5
4 - Distressing	17	4.3
5 - Very distressing	38	9.5
6 - Intense	30	7.5
7 - Very intense	39	9.8
8 - Utterly horrible	78	19.5
9 - Excruciating, unbearable	117	29.3
10 - Unimaginable, unspeakable	74	18.5
Total	400	100.0

Symptom change and antibiotic treatment

Participants were asked whether their chronic UTI symptoms were getting better or worse. They were also asked whether they were taking antibiotics, either full strength as a short-term or long-term treatment or at a lower ‘prophylactic’ dose (typically part of a longer-term management strategy for people diagnosed with recurrent UTI).

The cross tabulated results of these two questions (Table 11) show a clear trend towards long term treatment with antibiotics, especially at full strength, being associated with people who reported symptom improvement. The probability of these results occurring by chance, based on Chi-squared analysis, is less than 0.001.

Table 11:

Crosstabulation of symptom change and types of treatment

		Are you currently being treated with antibiotics?				Total
		Yes, currently being treated with full strength antibiotics for a protracted period	Yes, currently receiving short-term full-strength antibiotics	Yes, currently taking a low dose of antibiotics as a prophylaxis	No, I'm not taking antibiotics at the moment	
Which of the following statements best describes your chronic UTI symptoms?	I have had chronic UTI symptoms, but I am now almost cured	19 (9.5%)	0 (0.0%)	1 (2.3%)	18 (13.5%)	38 (9.3%)
	My chronic UTI symptoms are generally improving but I still have symptoms and/or flares	125 (62.5%)	4 (11.8%)	23 (53.5%)	52 (39.1%)	204 (49.8%)
	My chronic UTI symptoms are generally not getting better or worse	48 (24.0%)	15 (44.1%)	9 (20.9%)	41 (30.8%)	113 (27.5%)
	My chronic UTI symptoms are getting worse	8 (4.0%)	15 (44.1%)	10 (23.2%)	22 (16.5%)	55 (13.4%)
Total		200 (100%)	34 (100%)	43 (100%)	133 (100%)	410 (100%)



Perceived triggers for persistent UTI symptoms

“A UTI [that] never went away because they would not give me antibiotics after the initial 3 days. After 3 days symptoms returned, but they didn’t believe me due to negative tests.”

“I begged a doctor to give me some antibiotics as they were the only thing to relieve my painful symptoms. I was given a prophylactic dose. I believe this is when my infection became deeply embedded into my bladder.”

“An antibiotic-resistant initial UTI.”

“I find it important to mention that the following triggers are NOT causes of my chronic UTI, they are things that can cause my symptoms to exacerbate...My triggers are: sex, alcohol, sugar, exercise, tiredness, waking up early, lack of sleep, and stress.”

Just over half the participants (222 or 54.1%) said “yes” to a survey question asking them whether they recognised a trigger that preceded their persistent (intermittent or ongoing) UTI symptoms. These participants were then asked to explain in their own words what they thought triggered their condition. A wide range of responses were given, which were coded into the categories shown in [Table 12](#). The number of responses is greater than 222 because up to two different answers were coded per participant.

Table 12:

Participants’ beliefs about what triggered their persistent UTI symptoms

Perceived trigger	Number of responses	% of responses
Sex and/or other lifestyle factors (stress, alcohol, too much bike riding, holding on too long, being constipated, dehydrated)	107	44.6%
Inadequate treatment for acute infection (too short course of antibiotics/repeated sub-lethal courses/wrong antibiotic)	34	14.2%
Surgery/catheter/biopsies/ pelvic mesh/other procedures (e.g., cystoscopies)	29	12.1%
Menopause//pregnancy/ childbirth/miscarriage/ hormonal changes/getting old	22	9.2%
Acute UTI, including antibiotic resistant UTIs	20	8.3%
Other type of infection and/or underlying medical condition or medical treatment	17	7.1%
No treatment for infection (e.g., due to inadequate tests not detecting infections)	6	2.5%
Anatomical abnormality affecting urinary tract	5	2.1%
Total	240	100%

The answers indicated variability in the interpretation of the question: some participants focused on factors that led to or predisposed them to acute infections or flare-ups of chronic symptoms, while others explained why they thought a chronic UTI had developed.

By far the most common perceived trigger was sexual intercourse, which

is widely recognised among UTI sufferers as a trigger for acute UTI as well as flare-ups of chronic UTI symptoms. Other ‘lifestyle’ factors thought to trigger UTI included stress, alcohol and dehydration.

Thirty-four participants (14.2%) reported that inadequate treatment for acute UTI had triggered the formation of chronic UTI.

4.2 CURRENT HEALTH-RELATED QUALITY-OF-LIFE

As mentioned in [Section 2](#), our survey included the SF-12v2®, a 12-item questionnaire that asks about respondents' perceptions of their physical and mental health. The SF-12v2® is one of the most widely used instruments for assessing self-reported health-related quality-of-life and has been shown to be a valid and reliable measurement tool.⁹ It is for people aged 18 years and over and asks respondents to think about their health over the preceding four weeks.

[Attachment 2](#) provides the SF-12v2® questions and shows the number and percentages of participants who gave each response.

We commissioned Quality Metric to score the data using its proprietary software, PRO CoRE. Scores are calibrated so that 50 is the average score or norm, based on aged and gender-matched benchmarks from the United States general population.¹⁰ Scores are generated for the following eight health domains:

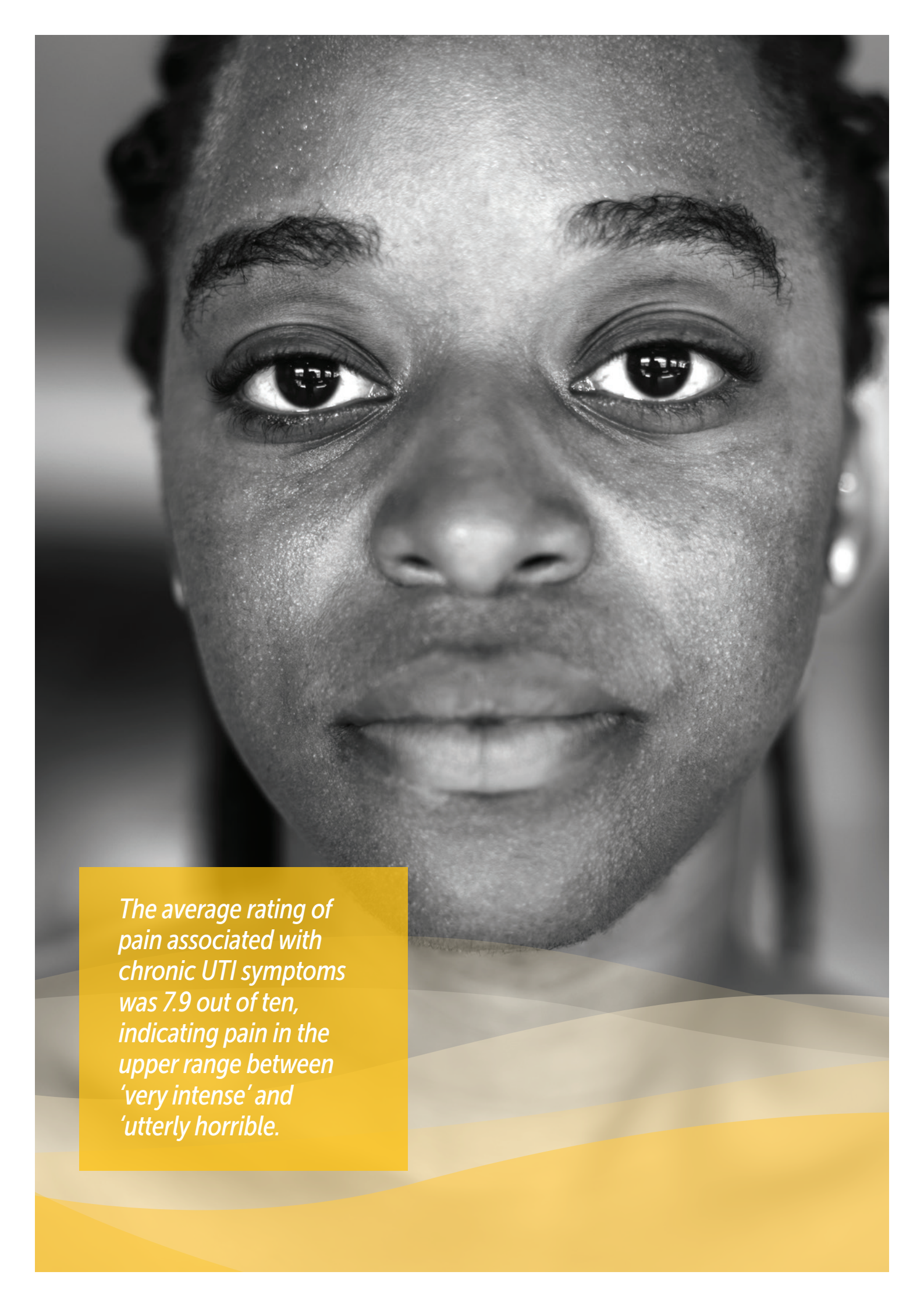
- 1. Physical functioning (PF)**
- 2. Physical role (limitations in usual role activities because of physical health problems, RP)**
- 3. Bodily pain (BP)**
- 4. General health (GH)**
- 5. Vitality (energy and fatigue, VT)**
- 6. Social functioning (SF)**
- 7. Role emotional (limitations in usual role activities because of emotional problems, RE)**
- 8. Mental health (MH).**

Each survey participant also received a physical component summary (PCS) and a mental component summary (MCS) score.

Quality Metric provided a Data Quality Evaluation report, which indicated that the quality of the data we collected using the SF-12v2® was 'excellent.'

The results of Quality Metric's norm-based scoring are shown in [Table 13](#). While these data are unsuitable for calculating statistical significance, the average scores of our participants were below the population average score (50) for all eight health domains and for the two summary measures. The biggest gaps between our population and the general population were in the 'bodily pain', 'physical role', 'social functioning', 'role emotional', and 'mental health' domains.





The average rating of pain associated with chronic UTI symptoms was 7.9 out of ten, indicating pain in the upper range between 'very intense' and 'utterly horrible.'

Table 13:
Scale and summary measure scores, norm-based scoring

	Scales							Summaries	
	PF	BP	GH	VT	SF	RE	MH	PCS	MCS
Mean (average)	45.31	41.01	46.01	43.38	39.09	38.43	38.87	45.45	38.25
25th percentile	33.45	30.67	33.84	39.23	30.22	30.29	29.79	37.80	30.44
50th percentile	49.19	39.69	47.75	39.23	39.11	40.69	41.26	47.07	38.39
75th percentile	57.06	48.71	57.69	49.07	48.01	45.89	47.00	53.85	46.35
Standard deviation	11.03	11.55	12.10	9.90	11.46	12.07	10.50	10.21	10.72
Minimum	25.58	21.66	23.90	29.39	21.32	14.70	18.32	19.74	12.80
Maximum	57.06	57.73	63.66	68.74	56.90	56.28	64.21	65.89	62.78
Number of responses	410	410	410	410	410	410	410	410	410

Included with the scores we received from Quality Metric were two categorical variables that compared the respondent’s physical component summary (PCS) and mental component summary (MCS) scores to an age- and gender- matched general population benchmark. The comparison is calculated such that if the respondent’s score is:

- less than five points below or higher than the benchmark, it was classified as the ‘same or better’ than the age and gender-matched general population.
- five to less than 10 points below the benchmark, it was classified as ‘below’ than the age and gender-matched general population.
- ten or more points below the benchmark, it was classified as ‘well below’ than the age and gender-matched general population.

This analysis does not indicate whether group-level scores are significantly different, in a statistical sense, from the general population, but it does provide information about the proportion of the sample that had what Quality Metric termed ‘clinically meaningful differences.’ The findings are shown in [Table 14](#).

Our participants had markedly worse mental and emotional health than the (age and gender matched) general population. Half of our sample had mental health component summary scores ‘well below’ the population norms and another 19% were ‘below’ the norm. In contrast, just over 40% of participants had a ‘clinically meaningful’ lower physical component summary score compared to the general population.

These results are consistent with findings presented earlier in this report:

- chronic UTI symptoms — and, frequently, difficulties in receiving appropriate diagnosis and treatment — are highly distressing (**Section 4.1**). Hence, mental health impacts are not surprising.
- the better standing of participants in terms of physical health, compared with mental health, may be related to our recruitment method. This relied heavily on membership of online support groups and may have resulted in underrepresentation of socially and economically disadvantaged groups. Research consistently shows that more advantaged and socially connected people tend to have better physical health overall.¹¹
- chronic UTI can and often does occur in people who are otherwise physically well (**Section 3.5**), and who therefore do not report high levels of overall physical dysfunction.

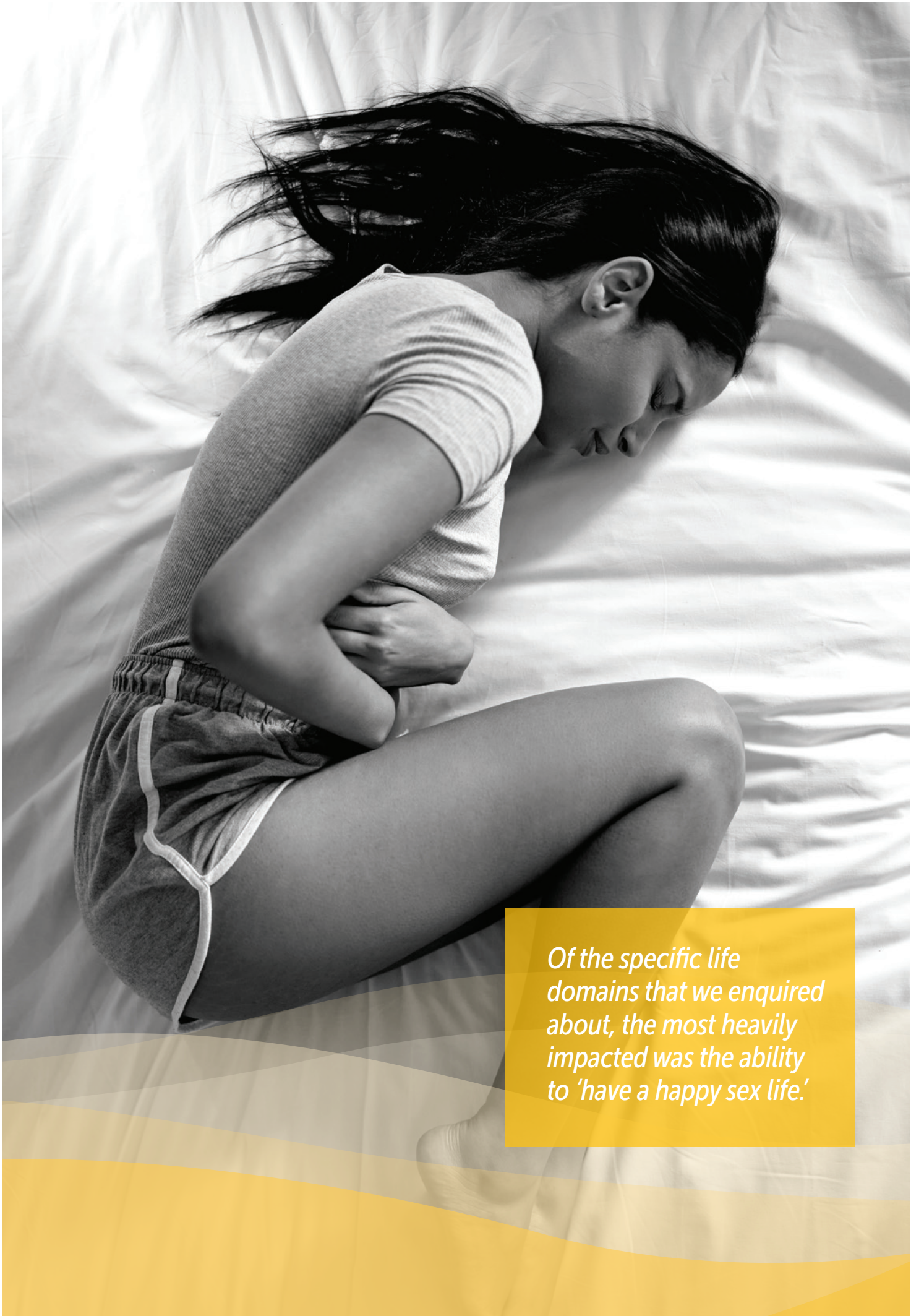
In the next section we consider in more detail the impact of chronic UTI symptoms on various life domains.

Table 14:

Number and proportion of participants with clinically meaningful differences compared with age and sex matched population benchmarks

	Physical component summary (PCS) scores	Mental component summary (MCS) scores
	Number (%)	Number (%)
Same (or better)	239 (58.3%)	124 (30.3%)
Well Below	109 (26.6%)	208 (50.7%)
Below	62 (15.1%)	78 (19.0%)
Total	410 (100%)	410 (100%)





Of the specific life domains that we enquired about, the most heavily impacted was the ability to 'have a happy sex life.'

4.3 IMPACT OF UTI SYMPTOMS ON LIFE DOMAINS

Participants were shown a list of various life domains and were asked to rate the extent to which their chronic UTI symptoms affected each domain. Ratings were made on a five-point scale ranging from ‘not at all’ to ‘extremely’. Participants were also given the option to indicate that the domain was ‘not applicable’ to them.

Attachment 3 presents the detailed results from this survey item. **Table 15** shows the number and percentage of respondents who were at least moderately impacted in each domain. Note that the data shown in the table excludes participants who rated the life domain as ‘not applicable.’

Of the specific life domains that we enquired about, the most heavily impacted (among the 358 participants who considered it ‘applicable’) was the ability to ‘have a happy sex life.’ This domain was impacted ‘moderately’ by 36 participants (8.8%); ‘quite a bit’ by 68 (16.6%); and ‘extremely’ by 193 (47.1%) of applicable participants. The fact that nearly half reported an extreme impact of chronic UTI symptoms on their sex lives was reflected in answers to our open-ended question at the end of the survey. The open-ended question invited participants to explain how chronic UTI symptoms had impacted their lives. As shown in **Table 15**, the impact on sex was one of the key themes of participants’ responses, with their answers indicating that their sex lives had been affected by painful intercourse and/or fear that sex would lead to a flare-up of their symptoms.

Table 15:

*Number and percentage of participants at least moderately impacted in various life domains**

Quality-of-life overall	384 (93.7%)
Having a happy sex life	297 (83.0%)
Feeling good about yourself	314 (77.1%)
Maintaining good mental and emotional health	304 (74.7%)
Travelling for leisure or work	268 (72.8%)
Ability to exercise for health and fitness	290 (72.1%)
Sleep	293 (71.5%)
Maintain a good relationship with your partner	256 (69.9%)
Doing enjoyable things outside the home	264 (65.5%)
Household tasks, such as cleaning, cooking and shopping	254 (62.7%)
Working as many hours as you would like to	217 (61.5%)
Parenting children	110 (59.4%)
Career progression	188 (59.1%)
Study, training or other skill development opportunities	183 (57.7%)
Developing and maintaining good relationships with friends and colleagues	223 (55.5%)
Managing finances	148 (38.8%)

* Excludes respondents who considered the domain ‘not applicable’

For all life domains except ‘managing finances’, a majority of participants (more than 50%) rated an impact of chronic UTI symptoms as at least ‘moderate’.

When asked to think about the effect of chronic UTI on their lives ‘overall’, the overwhelming majority of participants (93.7%) indicated at least a moderate impact. Approximately half the sample (49.3%) indicated an ‘extreme’ impact on their lives overall.

Participants’ free-text responses to our open-ended survey question on ‘how your life is or has been affected by your chronic UTI symptoms’ were coded using a basic thematic analysis technique. [Table 16](#) presents the key themes; the number and percentage of participants who volunteered information consistent with each theme; and verbatim examples of participants’ answers that were classified against each theme. Note that each participant’s answer to this question could be classified against more than one theme; hence, the percentages shown in [Table 16](#) add up to more than 100.

The most prominent theme, expressed by almost half (47.6%) of those who answered the question, was an indication that chronic UTI symptoms had had ‘global’ impact — that is, the symptoms had diminished overall quality-of-life or all areas of life.

Consistent with our previously reported findings on the mental health impacts of chronic UTI symptoms, nearly one in ten participants who answered this question volunteered — without prompting — that chronic UTI symptoms had left them feeling suicidal or that they had planned or attempted to take their own lives because of the condition.

[Table 16](#) also indicates that the impacts of chronic UTI symptoms may be compounded by negative interactions with health professionals. One in five participants (20.5%) who answered the open-ended question on the impacts on their chronic UTI volunteered information consistent with this theme. [Section 4.4](#) provides more information about participants’ experiences of seeking professional help for their chronic UTI symptoms.

Table 16:

Coded responses to open-ended question on ‘how your life is or has been affected by your chronic UTI symptoms’

Theme/Number (%) who volunteered information consistent with theme, of 361 participants answering question	Verbatim examples
Global impact — all areas of life affected; ‘ruined life’; housebound; bed ridden. 172 (47.6%)	“Life wasn’t worth living. Just everything. That’s the best way I can describe it.” “Due to extreme frequency, I am basically housebound with very little quality-of-life.” “It’s taken way all of my 20s...”
Feeling [constantly] sick and being in pain/never feeling well/physical distress. 106 (29.4%)	“I have lost 2 years of my life to agonizing pain.” “My body feels exhausted, like it’s always fighting off some infection.”
Impact on relationships (family, friends, partner, children). 103 (28.5%)	“I cannot visit my friends and family and not babysit my newborn grandchild. I am very lonely...” “I am now 45 and will not be a mother. UTI is one of the reasons why.” “My marriage broke up as a result of my bladder issues.”
Impact on work, study and/or finances. 98 (27.1%)	“I dropped out of university...and lost the job I loved.” “It...left me financially bankrupted almost and on benefits unable to work...I am now severely disabled and all I needed was antibiotics.”
Fear about not getting better/helplessness/hopelessness/constant fear of flare. 93 (25.8%)	“I feel so incredibly alone with this condition, trapped in a vortex of pain with no lifeline or way out.” “At their worst, symptoms have made me feel desperate and hopeless about the future.”
Impact on sex life. 85 (23.5%)	“We were trying to conceive, and we can’t even have intercourse anymore.”

<p>Specific mention of mental health impact or condition (anxiety, depression, PTSD; panic attacks).</p> <p>84 (23.3%)</p>	<p><i>"I have been diagnosed with PTSD from my experiences with UTIs."</i></p> <p><i>"Gone into depression as I feel I can never lead a normal life."</i></p>
<p>Distress related to interactions with health professionals (e.g., inability to find doctors willing/able to help; being disbelieved by health professionals; misdiagnosis; inappropriate treatments).</p> <p>74 (20.5%)</p>	<p><i>"It is a horrible feeling to not be believed or listened to when you are suffering beyond belief."</i></p> <p><i>"I feel I have been failed by the medical field and experienced years of unnecessary suffering."</i></p> <p><i>"...same old, same old 'no growth, no infection, no treatment'."</i></p> <p><i>"I just pray one day doctors in Australia are better educated about this terrible illness."</i></p>
<p>Relief at now being effectively treated and getting better.</p> <p>43 (11.9%)</p>	<p><i>"Now I'm having the correct treatment, my mental state is excellent as I know there's a light at the end of the tunnel."</i></p>
<p>Medical complications — e.g., kidney infection, sepsis, side effects of treatments.</p> <p>36 (10.0%)</p>	<p><i>"...finishing up in hospital with sepsis due to UTI."</i></p> <p><i>"...digestive issues as a result of excessive antibiotic use."</i></p>
<p>Suicidal ideation or attempt (directly mentioned).</p> <p>35 (9.7%)</p>	<p><i>"...tried to kill myself when I was diagnosed with IC because I thought my life would be less forever."</i></p> <p><i>"...kept me trapped in my house and in such excruciating pain I planned my own death."</i></p>
<p>Impact on sleep.</p> <p>31 (8.6%)</p>	<p><i>"I'm constantly getting up during the night for the toilet and it's excruciatingly painful every time I go."</i></p>
<p>Other specific impacts (e.g., inability to travel, do leisure activities; eat normally).</p> <p>100 (27.7%)</p>	<p><i>"I can't go swimming, horse-riding, bike riding, cannot walk around the block without needing to urinate urgently."</i></p>

4.4 EXPERIENCES OF SEEKING HELP FOR CHRONIC UTI SYMPTOMS

"I contemplated suicide because I felt so unheard. I have 3 small children with extra needs, and I only stayed alive for them."

Survey participants were shown a list of statements describing possible experiences of seeking help from health practitioners and asked whether that experience was true of their own experience of seeking help for chronic UTI. Ratings were made on a five-point scale ranging from 'strongly agree' to 'strongly disagree.'

Attachment 4 presents the detailed results from this survey item. [Table 17](#) shows the number and percentage of respondents who 'agreed' or 'strongly agreed' with each statement.

Most participants (82.0%) agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and treats chronic UTI. However, at the time of the survey, almost half the participants (49.0%) said they had access to a healthcare professional who understands chronic UTI. While it is concerning that half did not have such access, even more concerning is the fact that our participants — who were mainly recruited from UTI support groups — are likely to have much better access to a chronic UTI-competent health practitioner than people with chronic UTI symptoms who are not connected to online support groups. This is because information about chronic UTI specialists and doctors willing to follow evidence-based treatment protocols is routinely shared between members of support groups.

As shown in [Table 17](#), staggeringly high numbers of participants 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, including a mental health 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.

Even though 92.7% of participants had returned a negative urine culture test while experiencing UTI symptoms (see [Section 4.1](#)), only a minority (39.5%) had ever had it explained to them that 'gold standard' UTI diagnostic tests, such as dipsticks and urine cultures, can be inaccurate. Responses to a later open-ended survey question, discussed below, suggest that these participants were often those who had accessed specialist chronic UTI clinics or other health practitioners knowledgeable about chronic UTI. They typically received this information after many experiences of having their chronic UTI symptoms dismissed based on negative dipstick and urine culture tests.

A sizable minority of participants (43.6%) had experienced financial barriers to accessing effective treatment.



Table 17:
Number and percentage of participants who 'agree' or 'strongly agree' with statements about seeking help for chronic UTI symptoms

It has been difficult to find a healthcare practitioner who understands and can treat my chronic UTI	339 (82.6%)
I have felt that my symptoms have been dismissed or not believed by a healthcare professional	336 (81.9%)
I have been given unhelpful advice to change my behaviour	315 (76.8%)
I have been offered or given therapies that I believe were inappropriate and/or unhelpful	275 (67.1%)
A healthcare professional has told me that my chronic UTI symptoms are caused by another medical condition	273 (66.6%)
A healthcare professional has told me that there is nothing that can be done for my symptoms	264 (64.4%)
I have access to a healthcare professional who understands chronic UTI	201 (49.0%)
A healthcare professional has said or implied that I am doing something to cause or worsen my symptoms	188 (45.9%)
Finances have been a barrier to accessing effective treatment for my chronic UTI	179 (43.6%)
A healthcare professional has told me that my chronic UTI symptoms are caused by stress or mental health, emotional or relationship problems	167 (40.7%)
I have consulted with health professionals who explained to me that 'gold standard' UTI diagnostic tests, such as dipsticks and urine cultures, can be inaccurate	162 (39.5%)

Towards the end of the survey, participants had the opportunity to respond to an open-ended question asking them to describe how they felt about their interactions with health professionals when seeking help for chronic UTI symptoms. [Table 18](#) shows the results of our thematic analysis of the responses to this question. It shows the key themes; the number and percentage of participants who volunteered information consistent with each theme; and verbatim examples of participants' answers that were classified against each theme. Note that each participant's answer to this question could be classified against two or more themes; hence, the percentages shown in [Table 17](#) add up to more than 100.

While a few participants reported entirely negative experiences or (very rarely) entirely positive experiences, most responses described a mix of positive and negative experiences. For example, it was common for participants to say that they had experienced negative interactions with many doctors before they found a specialist in chronic UTI (or a non-specialist willing to follow an evidence-based chronic UTI treatment protocol) who had given them a correct diagnosis and effective treatment. Unfortunately, even when participants reported positive experiences — such as health professionals being kind and keen to help — they often went on to say that the practitioner was unable to offer effective treatment (typically because the practitioner lacked knowledge or was concerned about prescribing outside the current guidelines).

Table 18:

Coded responses to open-ended question asking participants to describe how they feel about their interactions with health professionals when seeking help to diagnose and treat chronic UTI symptoms.

Theme/Number (%) who volunteered information consistent with theme, of 375 participants answering question	Verbatim examples
Positive themes	
Received effective treatment/good care from specialist in chronic UTI. 57 (15.2%)	<i>"I only received positive care when I travelled outside my home country...to seek help from [name of chronic UTI specialist]."</i>
Practitioner was nice/sympathetic/ tried to be helpful. 52 (13.9%)	<i>"My GP genuinely wanted to help."</i>
Received effective treatment/ good care from GP or other health practitioner (including urologist who is not UTI specialist). Includes GPs agreed to follow protocol from chronic UTI specialist. 42 (11.2%)	<i>"My road to recovery started when I found a GP who was open minded to the latest evidence for diagnosing chronic UTI and treating with full dose, long term antibiotics."</i>
Received help with supplementary therapies. 5 (1.3%)	<i>"My naturopath...helps me with supplemental treatment while [I'm] under the care of my UTI specialist."</i>
Negative themes	
Dismissive/unhelpful/rude/ patronising/disbelieving/refused to treat/passed patient on to another practitioner/downplayed severity and impact. 194 (51.7%)	<p><i>"The urologist was patronising and dismissive of my symptoms."</i></p> <p><i>"I have huge anxiety from medical practitioners effectively gaslighting me about my UTI symptoms — they are all in my head, I'm causing my own symptoms, I "like" being sick, etc."</i></p> <p><i>"The Dr refused to make an [another] apt [appointment] with me."</i></p> <p><i>"One literally yelled at me to "stop saying it feels like a UTI"."</i></p> <p><i>"When I raised information about chronic UTI and presented some research papers...he became angry and red and aggressive."</i></p>
Doesn't understand/recognise chronic UTI and/or the inadequacy of standard tests/need to do own research. 131 (34.9%)	<p><i>"All the GPs spouted misinformed nonsense about UTIs (cranberry juice, tests can't be wrong, interstitial cystitis, you are too stressed etc etc)."</i></p> <p><i>"Medical practitioners here do not believe you can have a UTI with negative culture. "</i></p>
Unwilling/unable to prescribe long term antibiotics/Only prescribes short-term or low dose/prophylactic antibiotics/Haphazard antibiotic prescribing/Critical of patient for taking long-term antibiotics. 66 (17.6%)	<p><i>"They say they can't give more than 2 weeks antibiotics due to 'the rules'."</i></p> <p><i>"She had heard of people...treating with high dose long term abx [antibiotics] which she described as 'crazy'...I was prescribed low dose abx [antibiotic] which didn't work so well."</i></p>

<p>Unnecessary/ineffective/harmful investigations and/or treatments. 63 (16.8%)</p>	<p><i>"Multiple cystoscopies, bladder stretching, DC, prescribed the pill and Elmiron which made most of my hair fall out and cost me \$700 per month [but] did nothing for my pain."</i></p> <p><i>"Refuse to prescribe long term Abs [antibiotics] but very happy to coerce you into unnecessary and invasive procedures."</i></p>
<p>Misdiagnosis, including attributing symptoms to a mental health problem. 58 (15.4%)</p>	<p><i>"Urologist] said it was IC [interstitial cystitis] and nothing could be done."</i></p> <p><i>"GP explain[ed] to me that it could be an emotional issue or even pelvic floor dysfunction not an infection."</i></p>
<p>Unhelpful advice to change behaviour. 30 (8.0%)</p>	<p><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."</i></p>
<p>Unable/difficult to access specialist or preferred health practitioner due to long waits, high cost and/or distance issues. 23 (6.1%)</p>	<p><i>"They [specialists in chronic UTI] have so many patients now because other doctors don't have the knowledge that it's difficult to even get appointments."</i></p> <p><i>"I feel as if it's a rich person's disease."</i></p>

As shown in [Table 18](#), comments about negative experiences with health professionals far outweighed positive comments. The most common experience, reported by more than half of those who commented, was feeling 'dismissed', 'unheard', or 'not believed' by health professionals. While in most cases the perceived 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 participant and those who told their patient they would 'just have to live with' chronic UTI symptoms.

More than a third of participants who provided an answer to this question offered their opinion that medical professionals were generally ill-informed about current research on the uro-microbiome, UTI and chronic UTI diagnosis and treatment. Many answers indicated disbelief that even medical specialists — that is, urologists and uro-gynaecologists — could be unaware of research from at least the last decade showing 'gold standard' UTI diagnostic tests

are often wrong and can provide misleading information; that chronic, embedded UTI exists; and that protracted treatment with full strength antibiotics is an evidence-based (if not ideal) treatment for this condition.

As a corollary to health professionals' perceived lack of knowledge of chronic UTI, many participants reported having received or been offered what they considered to be unnecessary medications and procedures to address their chronic UTI symptoms. These interventions were not only inappropriate and ineffective in most cases, but many were invasive, had unpleasant and sometimes irreversible harmful side effects, caused pain, exacerbated symptoms, and were expensive.

Almost one in five participants commented on the difficulty getting doctors to prescribe the protracted antibiotic treatment they believed was necessary. While in many cases this was because the doctor did not agree that this treatment was indicated, some participants said their doctor had appeared worried about falling foul of guidelines and new antimicrobial stewardship policies designed to limit antibiotic prescribing to address concerns

of antimicrobial resistance. Several participants expressed a view that repeated short courses of antibiotics had contributed to the development of their chronic UTI.

In answer to the open-ended question about their experiences, only a small proportion (8.0%) of participants commented on being given unhelpful advice to change their behaviour as a way of preventing UTI recurrences. However, as shown in [Table 17](#), 76.8% agreed that this had occurred when presented with a list of possible experiences. Some of the examples given in response to the open-ended question were concerning. Along with advice that was merely ill-informed (such as being told to drink more water, consume cranberry products, and sit on the toilet longer), some participants reported that health professionals had made highly insensitive and inappropriate comments about their (presumed) sexual practices and lack of hygiene.

Finally, although many participants were grateful to have accessed a clinic specialising in chronic UTI, others had been unable to do this or were concerned about the waiting times and/or cost of this option.

4.5 USE OF HEALTH SERVICES

Our participants were asked how often they had used various types of health services in the last 12 months. We compared the results with the same question asked in an Australian Bureau of Statistics (ABS) survey of Australians over the age of 15 in 2020–21 (see [Table 19](#)).

Due to the possibility that health services' utilisation might be different in Australia compared with other countries, we compared the ABS

survey results with our results from participants resident in Australia, as well as with our whole sample.

Generally, Australian residents differed only marginally from the overall sample — except for GP and allied health usage, which was higher when Australians only were considered.

The comparison of our participants with a general sample of Australians showed a striking pattern of much higher health service utilisation among people with chronic UTI symptoms. As shown in [Table 19](#), the differences were most pronounced for resource

intensive services, such as medical specialists, hospitalisations and emergency department visits.


In terms of potentially preventable costs to the health system, it is alarming that our 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 were not suitable for gauging the extent of health costs due to chronic UTI, the results do indicate a high level of potentially avoidable expenditure. This is discussed further in [Section 5](#).

Table 19:

Use of health services in the last 12 months by selected characteristics: our survey participants compared with a general sample of Australians over 15 years of age

Use of health services in the last twelve months	Our survey participants: all (n=410)	Our survey participants: living in Australia (n=165)	Australian Bureau of Statistics survey of Australians over 15 years, 2019-20
Saw a general practitioner	350 (85.4%)	159 (96.4%)	82.4%
Saw GP for urgent medical care	117 (28.5%)	52 (31.5%)	8.2%
Saw an afterhours general practitioner	77 (18.8%)	31 (18.8%)	5.1%
Received a prescription for medication*	401 (97.8%)	163 (98.8%)	65.5%
Saw a medical specialist	280 (68.3%)	106 (64.2%)	37.4%
Had a pathology test	336 (82.0%)	148 (89.7%)	58.4%
Had an imaging test	253 (61.7%)	110 (66.7%)	37.7%
Admitted to hospital	115 (28.0%)	57 (34.5%)	12.5%
Visited hospital emergency department	152 (37.1%)	61 (37.0%)	13.4%
Saw three or more health professionals for the same condition	186 (45.4%)	77 (46.7%)	16.5%
Saw an allied health professional	143 (34.9%)	80 (48.5%)	NOT ASKED
Saw a mental health professional	153 (37.3%)	61 (37.0%)	NOT ASKED
Saw provider of alternative or complementary healthcare	144 (35.1%)	62 (37.6%)	NOT ASKED

* Asked only in relation to medication for chronic UTI symptoms



More than 80% of participants had difficulties finding a healthcare practitioner who understands and can treat chronic UTI.

DISCUSSION

In this section, we discuss the implications of our survey in terms of four key themes that emerged from the findings:

- Diagnostic and treatment failures
- Severe quality-of-life impacts
- Poor experiences of healthcare
- Avoidable costs to the health system.

5.1 DIAGNOSTIC AND TREATMENT FAILURES

The survey results strongly support scientific research discrediting the accuracy of existing 'gold standard' diagnostic methods for detecting UTI and demonstrate the challenges of accessing effective treatment for chronic UTI.

The findings highlight the need for up-to-date information about UTI testing to be included in health professionals' training and education, as well as for new professional guidelines on treating chronic UTI and other forms of hard-to-treat UTI.

Inadequate UTI tests

As evidenced by the research cited in [Table 20](#), urinary dipsticks and mid-stream urine (MSU) culture tests are proven to have high rates of failure to detect genuine infections and were never designed to exclude infection. These failures are amplified in cases when the infection has become embedded and chronic as, in contrast to acute UTI, there are relatively few free-floating bacteria in the person's urine.

Over 90% of our survey participants had returned a negative urine culture test while experiencing UTI symptoms. Research using alternative diagnostic methods, such as polymerase chain reaction (PCR techniques), show that most people who report symptoms of a UTI but return a negative culture, do in fact harbour uropathogens in their urine. Whether growing or identifying a uropathogens proves causation is still being determined by UTI researchers. In the meantime, it is harmful to patients to ignore research showing that current testing methods and guidelines are unsuitable for diagnosing UTI or conclusively identifying the pathogen responsible. Ironically, it appears that symptoms are currently the best indicator of infection.¹²



Our participants reported a range of UTI symptoms. While some symptoms – such as stress urinary incontinence – were variably reported, others were very common. Pain was reported by almost all participants (97.6%), urinary frequency by over 90%, and ‘cloudy, smelly or bloody urine’ by over 80%. In the absence of readily accessible and reliable diagnostic tests for UTI, many UTI experts are finding that patients’ symptoms, and their response to antibiotics, is preferable to unreliable diagnostic tests confirming the presence of a UTI.¹³

Participants’ answers to the open-ended survey question suggest that many health professionals, including urologists as well as general practitioners, are unaware that standard UTI tests can be unreliable. Although most participants had been diagnosed with chronic UTI by a health professional at the time of the survey, such diagnoses had often been delayed due to test results falsely indicating that no infection was present and had often required visits to many different health professionals over years or even decades.

A recent New Zealand study has reported on the significant negative quality-of-life impacts of diagnostic delays for patients with endometriosis and other forms of chronic pelvic pain.¹⁴

Diagnostic delays are often lengthy, as discussed in a recently published scientific journal article. The authors stated that:

“Worryingly, if these ‘gold standard’ tests produce false negative results, this could lead to erroneous diagnoses of overactive bladder and interstitial cystitis or bladder pain syndrome, which by definition present with similar LUTS in the absence of an infection...Because of this, patients with chronic UTI often describe a delay, sometimes up to 12 years.”¹⁵

Our survey findings indicate that people in Australia may find it more difficult to obtain a diagnosis of chronic UTI than people in other developed countries. Compared with other participants, Australians in the sample were significantly less likely to have been diagnosed with chronic UTI by a health professional: 72.8% of the Australian survey participants had been diagnosed by a health professional, compared with 83.7% of international participants. Further, 27 of the 120 Australians who had been diagnosed by a health professional had received their diagnosis overseas: several commented that they had to travel or seek online appointments with specialist UTI clinics overseas. Several participants commented that they incurred significant expense for travel and/or online appointments.

As noted previously, the relatively high rates of chronic UTI diagnosis among our participants reflect the fact that they were recruited from online support groups, in which members often share details of chronic UTI-informed health professionals and/or information about chronic UTI that they can share with their own doctors. Our participants frequently commented on the difficulty they had obtaining a diagnosis before they had access to patient-focused information. This is not surprising given that chronic UTI is not officially recognised by the medical community in Australia, and even overseas there are few clinics specialising in the management of chronic UTI or complex lower urinary tract symptoms (LUTS).

Misdiagnosis

Due to the proven deficiencies of UTI tests and poor understanding of chronic UTI, almost two thirds of participants had received alternative diagnoses to explain their lower urinary tract symptoms. The most common alternative diagnoses, reported by 226 participants (55.1%) were ‘interstitial cystitis’ (IC) or ‘painful bladder syndrome’ (PBS).

IC/PBS has long been described as a ‘diagnosis of exclusion’. This means it is a diagnosis given when all possible causes of ongoing LUTS have been explored and excluded, including and most especially, infection. Chronic UTI Australia’s website details our concerns with the IC/PBS diagnosis (at www.chronicutiaustralia.org.au/interstitial-cystitis-bladder-pain-syndrome/). Fundamentally, because dipsticks and urine cultures are incapable of excluding infection, negative results on these tests cannot be used to support an IC/PBS diagnosis. While we do not dispute that there can be other causes of the symptoms that lead to a diagnosis of IC/PBS, we believe that for a significant group of people, the underlying cause of their symptoms is not an incurable ‘syndrome’, but a challenging, although treatable, chronic infection.

Misdiagnosing a chronic infection as an incurable urinary syndrome not only denies the person the opportunity to be correctly treated for chronic UTI, but in many cases means they are subject to ineffective and potentially harmful interventions to relieve their supposed IC/PBS. As discussed in **Section 5.3**, this contributes to the poor experience of healthcare reported by many of our participants.

Table 20:

Selected papers on problems with standard UTI tests

- Urinary dipsticks, used by GPs as a first-line UTI diagnostic tool, are grossly insensitive and miss up to 70% of urinary infections.¹⁶ Midstream urinary cultures (MSU), considered the ‘gold standard’ to identify bacteria, are shown through research to miss from 50-80% of urinary infections.¹⁷ Recent research in the United Kingdom has found MSU cultures cannot distinguish chronic UTI patients from normal, asymptomatic controls.¹⁸
- There are more than 50 peer-reviewed papers since the 1980s highlighting problems with UTI treatment, guidelines and dipstick and MSU tests, but medical authorities ignore the evidence.^{19 20 21 22 23 24 25 26 27}
- Mounting scientific evidence suggests patients with lower urinary tract symptoms may harbour a UTI despite negative tests.²⁸

Concerns about antibiotic prescribing

Unfortunately, antibiotic treatment for acute UTI is far from perfect. Studies show that between 25-35% of people prescribed antibiotics for a UTI will fail, or not fully respond to, treatment.²⁹ We suspect inadequate treatment of acute UTI could be a key driver of recurrent and chronic infections. As some survey participants noted, fears about falling foul of guidelines designed to limit antibiotic prescribing are causing doctors to prescribe courses of antibiotics that are too short to clear many UTIs. Hence, survey participants described being

put on and off short courses of antibiotics over long periods or being offered longer term treatment only at low (prophylactic) doses. This undertreatment can result in worsening symptoms and a need for more antibiotics in the longer term because ‘sub-inhibitory’ antibiotic courses can lead to chronic and difficult-to-treat infections. [Table 21](#) cites popular treatment recommendations for acute and recurrent UTI (in Australia) and a sample of articles discussing the problems caused by under-treatment of common forms of UTI, and how this may lead to the development of chronic embedded infections.

UTI Treatment

While the survey was not designed to test the effectiveness of treatment for chronic UTI, we note that participants receiving long term treatment with antibiotics, especially at full strength, were significantly more likely than other participants to report that their symptoms were improving. The proportion of 'symptom improvers' being treated with a lower 'prophylactic' dose of antibiotics (typically part of a longer-term management strategy for people diagnosed with recurrent UTI) was lower than among people on full strength antibiotics, but still higher than people not receiving any antibiotic treatment or those being treated with short-term antibiotics.

These results are consistent with findings reported in peer-reviewed scientific literature. There is evidence that chronic, embedded infections can be cleared with continuous use of full strength, narrow spectrum antibiotics, which are often required for a protracted period.³⁰ Although prophylactic antibiotic treatment appeared successful for some of our participants, we note the concerns of researchers and medical experts that this form of treatment can lead to antibiotic resistance³¹ and, by delivering a constant but sub-lethal dose of antibiotics, may suppress rather than cure a chronic, embedded infection.³²

While some participants appeared to have developed a chronic UTI without a strong history of acute UTI (for example, after one infection resulting from a catheter insertion), it was more common for people to have had repeated acute infections before their symptoms become chronic. The survey data suggest that there is an average period of 8.5 years between a first UTI and the onset of persistent symptoms indicating a chronic UTI.

Table 21:

Selected papers on challenges in treating recalcitrant urinary tract infections

- People who present with symptoms of a UTI, treatment will most likely be a short course of first-line antibiotics, such as trimethoprim 300 mg orally at night for three days or nitrofurantoin 100 mg, six-hourly for five days. However, research has found that between 25–35% of patients will fail this treatment³⁴ and may go on to develop complications or an embedded infection.
- For those who have standard culture tests that grow resistant pathogens, there are alternative antibiotics that can be prescribed. There are currently no treatment guidelines for the sub-group of patients who fail, or do not fully respond to, standard UTI therapy and fall outside these parameters (e.g., those whose MSU culture reports are interpreted as 'negative').
- For someone in Australia with recurrent UTI (i.e., repeat UTIs that test positive using standard cultures), existing treatment guidelines include a trial of long-term prophylaxis (low-dose antibiotics to prevent further infections), self-start therapy or post-intercourse prophylaxis.³⁵
- A 3-day course of antibiotics is similar in effect to a prolonged course (5–10 days) in achieving symptomatic cure but is not as effective in achieving complete bacterial eradication.³⁶
- Once a UTI has progressed to a chronic form, it can become difficult to treat. However, there is evidence that the infection can be cleared with a protracted course of full-dose first-generation antibiotics.³⁷

There is, therefore, potentially a substantial window for proper treatment and prevention of acute and recurrent UTI, which may help reduce the risk of symptoms becoming persistent or chronic. A recently published scientific study suggests that the inaccuracy of diagnostic tests and inappropriate use of antibiotics in managing prior UTIs, possibly over many years, may shape the patient's response to subsequent UTIs.³³

Chronic UTI Australia wants to see fast, safe and effective alternatives to antibiotics for the treatment of acute and chronic UTI. As some survey participants had experienced, antibiotics can cause unpleasant side effects and are often required for a protracted period. However, while we await the alternatives, antibiotics are often the only effective treatment for patients with acute, recurrent and chronic UTI. The denial of antibiotics to this patient group (of mostly women) because of concerns of driving antimicrobial resistance and meeting antimicrobial stewardship targets, comes at a high personal cost to patients and a high moral and financial cost to the health system.

5.2 SEVERE QUALITY-OF-LIFE IMPACTS

When treatment is delayed or inadequate, UTI can become chronic and debilitating.

Our participants had suffered severe pain and quality-of-life impacts, typically for years and sometimes decades.

Throughout the presentation of survey findings in **Section 4**, we gave voice to people suffering with chronic UTI symptoms. The numerous quotes from material written by the survey participants lays bare the devastating impacts that this condition has on people's quality-of-life.

Although we were aware of these impacts before conducting the survey, it was difficult to read the countless harrowing descriptions of how participants' lives had been derailed by extreme pain, urinary frequency and other debilitating symptoms. In the worst cases, participants were housebound, had lost their livelihoods and close relationships, and saw little hope for the future. Equally distressing were the many accounts of patients being poorly treated in the health system. Some participants did report being treated with kindness, respect and understanding, but they were very much in the minority.

When asked to think about the effect of chronic UTI on their lives 'overall', the overwhelming majority of participants (93.7%) indicated at least a moderate impact. Approximately half the sample (49.3%) indicated an 'extreme' impact on their lives overall.



Of the specific life domains that we enquired about, the most heavily impacted was the ability to 'have a happy sex life.' Approximately half the 358 participants who considered this question applicable reported an 'extreme' impact of chronic UTI symptoms on their sex lives. In response to an open-ended question inviting participants to explain in their own words how their symptoms had affected their lives, impacts on intimate relationships were one of the most common themes – with participants explaining that their ability to have and enjoy sex had been affected by painful intercourse and/or fear that intercourse would lead to a flare-up of their UTI symptoms.

A range of other life domains were also impacted. For all life domains except 'managing finances', 50% or more of the participants rated the impact of chronic UTI symptoms as at least 'moderate'. These include domains relating to education, work and career, travel and leisure, personal relationships, parenting, exercise, sleep and managing household tasks.

Unsurprisingly given these impacts, many participants were profoundly distressed by their chronic UTI symptoms. As a group, they had markedly worse mental and emotional health than the (age and gender matched) general population. Half of our sample had mental health component summary scores 'well below' the population norms and another one in five were 'below' the norm. Nearly one in ten participants who answered our open-ended question on the impacts of chronic UTI volunteered – without prompting – that their symptoms had left them feeling suicidal or that they had planned or attempted to take their own lives because of the condition. While this finding is shocking, as advocates for people with chronic UTI we are unfortunately familiar with the extreme levels of distress experienced by some patients and the tragic occurrence of suicides related to the condition.³⁸

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.”³⁹



A recent study examined women’s experiences of interstitial cystitis/painful bladder syndrome (IC/PBS). Like our survey participants, the women in the IC/PBS study reported negative impacts on sexual and social relationships and ‘limitations’ on their lives generally. The authors of the study also noted that their participants had typically undergone numerous treatments with limited success.⁴⁰

These studies add to evidence that even uncomplicated forms of UTI have a negative impact on patients’ quality-of-life. In a qualitative analysis exploring the emotional impact of urinary tract infections in women, major themes included ‘negative emotions due to UTI symptoms’, ‘interference with activities of daily life, and effects on relationships and sleep’; (2) ‘varied emotions and understanding related to UTI treatment and management approaches’; (3) ‘treatment failure causing frustration, worry, and anger’; and (4) ‘dread and helplessness’ related to the prospect of recurrent UTIs.⁴¹ In a recently published study of 375 adult women who had experienced at least one UTI in the previous 60 days, researchers concluded that UTIs were associated with activity impairment, decreased productivity, and reduced health-related quality-of-life. Similar to the present study, the researchers found that their participants had higher healthcare costs compared with a matched population.⁴²

5.3 POOR EXPERIENCES OF HEALTHCARE

Experiences of feeling 'dismissed', 'belittled' and 'disbelieved' by medical professionals exacerbated the distress caused by the condition itself. Many participants reported that a lack of understanding of UTI by medical professionals had led to misdiagnosis and ineffective and potentially harmful medical and surgical treatments.

More than eight in ten survey participants had felt dismissed or not believed by a healthcare professional when seeking help for chronic UTI symptoms. 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.

Overall, 255 (62.2%) of participants had received an alternative diagnosis to explain their chronic UTI symptoms. Most concerning, 71 (17.3%) had received a mental health 'diagnosis'. Attributing chronic pain or other unexplained physical symptoms to a mental health or emotional problem is a form of medical gaslighting that is increasingly being called out in academic literature^{43,44} and among patient communities. Reflecting the traditional power differential between doctors and patients, the comments of many of our survey participants revealed that some health practitioners are unfortunately unwilling to listen to their patients and consider the limitations of their own knowledge.

We note, as did several survey participants, that dismissive or complacent attitudes towards women with chronic UTI symptoms is an example of gender bias in healthcare and medical research. Awareness of gender bias has become well established in public discourse over recent years. Gender bias has been identified specifically in relation to health professionals' responses to women experiencing chronic pain,⁴⁵ especially pelvic pain.⁴⁶ Women's pelvic pain conditions that, historically, have been underestimated and poorly recognised in medical practice include endometriosis⁴⁷ and pelvic mesh injury.⁴⁸ While these conditions have fortunately attracted much more attention from health professional bodies and research funders in recent years – thanks in no small part to the efforts of patient advocates – chronic UTI remains a neglected condition.

Some survey participants reported experiences of outright hostility or rudeness from health professionals; however, negative experiences of healthcare were for the most part due to doctors not being aware of current evidence about the diagnosis and management of UTI. Indeed, most survey participants (82.0%) agreed or strongly agreed that it had been difficult to find a healthcare practitioner who understands and treats chronic UTI.

It is of grave concern to Chronic UTI Australia that so many health professionals appear to be uninformed about the poor reliability of standard UTI tests and evidence-based approaches to treating UTI. As well as the potential for worsened UTI symptoms through withholding of effective treatment, we are concerned that so many survey participants – even those who had eventually found a medical practitioner to help them – reported having lost trust in the medical profession generally. The profound anxiety that some 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.

Chronic UTI is one of several health conditions predominantly affecting women that have been neglected in medical research and practice. While conditions such as endometriosis and pelvic mesh injury are finally getting the attention they deserve, chronic UTI remains poorly recognised and treated.

5.4 AVOIDABLE COSTS TO THE HEALTH SYSTEM

Participants used medical services much more frequently than the general population. The resulting costs to the healthcare system could be avoided with better understanding, diagnosis and treatment of UTI.

Our survey was not designed to quantify the financial costs associated with chronic UTI. Nonetheless, the evidence we collected highlights the avoidable burden to the health system caused by poorly diagnosed and treated UTI. The findings we reported in **Section 4.5** indicate that people with chronic UTI symptoms utilise health services much more than the general population. Each year they are more likely to:

- see a general practitioner, including for urgent care.
- see multiple specialist practitioners.
- attend after hours services.
- have tests (pathology, imaging).
- attend an emergency.
- be admitted to hospital.

Participants in our study described seeking help from multiple different health professionals as they grew increasingly desperate for relief from chronic severe pain and other debilitating symptoms. Noting similar findings, the authors of a United States study of women with ‘self-reported chronic UTI’⁴⁹ referred to the women as having ‘persistent care seeking behaviour’. Contrary to the implication of this assertion, people with chronic UTI are not seeking sympathy and/or attention: they are looking for effective treatment for a condition that impacts severely on their quality-of-life.

Our survey data add to existing evidence about avoidable health system costs due to UTI. Chronic UTI Australia’s 2019-20 annual report⁵⁰ presented evidence that serious UTIs are placing a growing burden on Australia’s health care system. We analysed data from the Australian Institute of Health and Welfare showing that the rate of hospital admissions for UTI grew by a staggering 81.6% between 1998 and 2017. The increase was present in both sexes and crucially, across all age groups — indicating that it was not an artefact of the ageing population.

Our survey results also support recent analysis from the national consortium Outbreak, led by the University of Technology, Sydney, which concluded that UTIs are becoming harder to treat, with more patients ending up in hospital and using more medical resources.⁵¹ Based on calculations using national and regional data from the Illawarra Shoalhaven Local Health District, the report’s authors estimated that there were more than 2.5 million general practice (GP) appointments, 100,000 emergency visits and 75,000 hospital stays each year for UTIs.

The report put the total annual cost of UTIs on Australia’s health system at \$909 million, but that estimate didn’t include indirect productivity losses, which are the largest contributor to the economic burden associated with chronic pain.⁵² One of the report’s authors, Associate Professor Branwen Morgan, was quoted in the media as saying, “those figures are very conservative and don’t take into account the increasing numbers of people with UTIs, so realistically it could cost much, much more than that.”⁵³

We would add that the research cited above also doesn’t consider people who have infections that are not picked up by the current inadequate tests. When raising our concerns about these tests with the then federal health minister, Chronic UTI Australia received a reply stating that 4.5 million Australians received a Medicare-funded urine culture test at a taxpayer cost of nearly \$80m in 2017-18. We were assured that “every health dollar contributes to improving Australia’s health care system, including the testing and treatment of UTIs.” On the contrary, we believe that continuing to use a test that modern science has refuted and attempting to treat UTI sufferers based on inaccurate information, is a misuse of taxpayers’ money.

NEXT STEPS

The survey has provided robust data about the quality-of-life and broader impacts of chronic UTI. The data is valuable from a research perspective, as chronic UTI is a neglected and (in Australia) officially unrecognised condition. People with chronic UTI are too often 'unheard', both as individual patients and as part of the advocacy groups that now exist in many parts of the world.

Our research is the first of its kind in Australia. At the time we conducted the survey, there had been very few studies worldwide examining the quality-of-life of people suffering from chronic UTI.

Importantly, the survey results allow Chronic UTI Australia to better understand our patient community and provide us with targeted and actionable information for our next round of communications with professional groups, researchers, government decision-makers and the media.

The survey findings have many implications for policy and practice changes relating to the diagnosis and management of UTI. Specifically, our findings indicate the need for:

- Education of and resources (including new professional guidelines) for health professionals, specifically in understanding and applying contemporary scientific evidence about UTI diagnosis and treatment.
- Education of the public, especially high-risk groups such as young women.


- More specialist clinics dedicated to chronic and complex UTI presentations, especially in Australia, where no such clinics currently exist. The planned new Australia-wide pelvic pain clinics provide an opportunity to introduce dedicated chronic UTI specialists to the health system.⁵⁴

- More research funding, especially for applied and translational research to deliver reliable diagnostic methods and safer, faster effective treatments for UTI.

- Open communication and positive engagement between patient groups, health professionals, researchers and policy makers.

More information about the matters raised in this report is available at www.chronicutiaustralia.org.au





People with chronic UTI are too often 'unheard', both as individual patients and as part of the advocacy groups that now exist in many parts of the world.

ATTACHMENT 1: PARTICIPANT INFORMATION STATEMENT

Chronic UTI Australia's 'Hearing Patient Voices' is a confidential online survey of people who have been diagnosed with a chronic urinary tract infection (UTI) or who suspect they have a chronic UTI. The survey is designed to capture the impacts of the condition on various domains of life.

Who is conducting this survey?

The survey is being conducted by Chronic UTI Australia Incorporated. Deirdre Pinto, Secretary of Chronic UTI Australia, is leading the survey. You can read about the mission, goals and work of Chronic UTI Australia on its website.

Chronic UTI Australia has received funding for the survey from Community Underwriting, and has commissioned a professional survey research company, Websurvey, to help develop the survey and to host it on a secure online portal.

What is the purpose of the project?

The 'Hearing Patient Voices' survey is a first-of-its-kind, capturing novel information about the impacts of chronic UTI on the individual, and the potential costs to the health system (for example, because of medical visits, diagnostic tests, surgical procedures and UTI related hospital admissions) and society in general (loss of productivity).

Chronic UTI is under-researched and poorly recognised and understood by health professional and policy makers. The voices of people affected by this condition are critical to overturning the longstanding neglect of this increasing public health problem.

The contribution of every person who participates in our survey will strengthen our understanding of patients' experiences.

What am I being asked to do?

You are being asked to complete an online survey by using the link provided to you in the email invitation.

The time needed to complete the questionnaire will vary depending on how much detail you wish to give in response to the survey's open-ended (free text questions). As a guide, we recommend that you allow 20-30 minutes to complete the questionnaire. If you are interrupted, your responses will be saved, and you can come back at finish it later.

Are there any risks of the participating in the survey?

Many of the questions in the survey ask you to reflect on your experience of having UTI symptoms. Although we hope this is not the case, thinking about your illness may induce negative feelings. If so, we encourage you to seek support from family, friends, a trusted health professional, or other familiar supports. If you are in crisis, please contact Lifeline on 131114 or Beyondblue on 1300 22 4636.

How will my confidentiality be protected?

When providing data from the survey to Chronic UTI Australia, Websurvey will not link the completed questionnaires to email addresses unless you give your permission (at the end of the survey) for this to occur. This means your identity will not be known to Chronic UTI Australia unless you choose to allow this.

Chronic UTI Australia will report the results of the survey as group data only, and participant's individual information will not be identifiable in the report. The final report may

include quotes from respondents but identifying information will be removed. If the organisation wishes to use quotes or responses that could be attributed to an individual, and you have allowed your email address to be linked to your survey responses, your written permission will be obtained before including this information in our report.

Will I receive feedback?

Once the survey has been completed, a summary of the overall findings will be available to respondents. After completing the questionnaire, you will be given the opportunity to indicate whether you wish to receive this summary report.

Do I have to take part?

Participation in this study is voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so.

Where can I get further information?

Please contact Deirdre Pinto from Chronic UTI Australia if you have any questions or if you would like more information about the project. Contact telephone numbers and email addresses are shown below.

Deirdre Pinto

deirdre@chronicutiaustralia.org.au

ATTACHMENT 2: UNSCORED RESPONSES TO THE SF-12V2® QUESTIONNAIRE

Question	Response categories	Number of respondents	% of respondents
In general, would you say your health is:	Excellent	25	6.1
	Very good	118	28.8
	Good	137	33.4
	Fair	82	20.0
	Poor	48	11.7
	Total	410	100.0
Does your health now limit you: doing moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	103	25.1
	Yes, limited a little	142	34.6
	No, not limited at all	165	40.2
	Total	410	100.0
Does your health now limit you: climbing several flights of stairs	Yes, limited a lot	63	15.4
	Yes, limited a little	138	33.7
	No, not limited at all	209	51.0
	Total	410	100.0
During the past 4 week how much of the time have you accomplished less than you would like as a result of your physical health?	All of the time	66	16.1
	Most of the time	86	21.0
	Some of the time	121	29.5
	A little of the time	69	16.8
	None of the time	68	16.6
	Total	410	100.0

Question	Response categories	Number of respondents	% of respondents
During the past 4 week how much of the time were limited in the kind of work or other activities as a result of your physical health	All of the time	63	15.4
	Most of the time	69	16.8
	Some of the time	133	32.4
	A little of the time	71	17.3
	None of the time	74	18.0
	Total	410	100.0
During the past 4 week how much of the time have you accomplished less than you would like as a result of any emotional problems?	All of the time	51	12.4
	Most of the time	83	20.2
	Some of the time	111	27.1
	A little of the time	89	21.7
	None of the time	76	18.5
	Total	410	100.0
During the past 4 week how much of the time did you do work or other activities less carefully than usual as result of any emotional problems?	All of the time	30	7.3
	Most of the time	62	15.1
	Some of the time	118	28.8
	A little of the time	102	24.9
	None of the time	98	23.9
	Total	410	100.0
During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	Not at all	68	16.6
	A little bit	115	28.0
	Moderately	87	21.2
	Quite a bit	89	21.7
	Extremely	51	12.4
	Total	410	100.0

Question	Response categories	Number of respondents	% of respondents
How much of the time during the past 4 weeks have you felt calm and peaceful?	All of the time	3	.7
	Most of the time	70	17.1
	Some of the time	147	35.9
	A little of the time	139	33.9
	None of the time	51	12.4
	Total	410	100.0
How much of the time during the past 4 weeks did you have a lot of energy?	All of the time	4	1.0
	Most of the time	57	13.9
	Some of the time	135	32.9
	A little of the time	126	30.7
	None of the time	88	21.5
	Total	410	100.0
How much of the time during the past 4 weeks have you felt downhearted and depressed?	All of the time	38	9.3
	Most of the time	92	22.4
	Some of the time	148	36.1
	A little of the time	102	24.9
	None of the time	30	7.3
	Total	410	100.0
During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities?	All of the time	62	15.1
	Most of the time	88	21.5
	Some of the time	115	28.0
	A little of the time	79	19.3
	None of the time	66	16.1
	Total	410	100.0

ATTACHMENT 3: IMPACT OF CHRONIC UTI SYMPTOMS ON LIFE DOMAINS (DETAILED)

Table X: Ratings of the extent to which chronic UTI symptoms affect life domains

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Do household tasks, such as cleaning, cooking and shopping		
All of the time	39 (9.5%)	254 (62.7%)
Most of the time	112 (27.3%)	
Some of the time	109 (26.6%)	
A little of the time	95 (23.2%)	
None of the time	50 (12.2%)	
Total	5 (1.2%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Work as many hours as you would like to		
Not at all	48 (11.7%)	217 (61.5%)
A little bit	88 (21.5%)	
Moderately	61 (14.9%)	
Quite a bit	95 (23.2%)	
Extremely	61 (14.9%)	
Not applicable	57 (13.9%)	

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Progress in your career		
Not at all	80 (19.5%)	188 (59.1%)
A little bit	50 (12.2%)	
Moderately	52 (12.7%)	
Quite a bit	56 (13.7%)	
Extremely	80 (19.5%)	
Not applicable	92 (22.4%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Pursue study, training or other skill development opportunities		
Not at all	75 (18.3%)	183 (57.7%)
A little bit	59 (14.4%)	
Moderately	53 (12.9%)	
Quite a bit	62 (15.1%)	
Extremely	68 (16.6%)	
Not applicable	93 (22.7%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Manage your finances		
Not at all	157 (38.3%)	148 (38.8%)
A little bit	76 (18.5%)	
Moderately	56 (13.7%)	
Quite a bit	56 (13.7%)	
Extremely	36 (8.8%)	
Not applicable	29 (7.1%)	

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Travel for leisure or work		
Not at all	42 (10.2%)	268 (72.8%)
A little bit	76 (18.5%)	
Moderately	75 (18.3%)	
Quite a bit	95 (23.2%)	
Extremely	98 (23.9%)	
Not applicable	24 (5.9%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Exercise for health and fitness		
Not at all	34 (8.3%)	290 (72.1%)
A little bit	78 (19.0%)	
Moderately	79 (19.3%)	
Quite a bit	98 (23.9%)	
Extremely	113 (27.6%)	
Not applicable	8 (2.0%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Do things you enjoy outside the home		
Not at all	37 (9.0%)	264 (65.5%)
A little bit	102 (24.9%)	
Moderately	87 (21.2%)	
Quite a bit	93 (22.7%)	
Extremely	84 (20.5%)	
Not applicable	7 (1.7%)	

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Maintain good mental and emotional health		
Not at all	22 (5.4%)	304 (74.7%)
A little bit	81 (19.8%)	
Moderately	99 (24.1%)	
Quite a bit	96 (23.4%)	
Extremely	109 (26.6%)	
Not applicable	3 (0.7%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Maintain a good relationship with your partner		
Not at all	36 (8.8%)	256 (69.9%)
A little bit	74 (18.0%)	
Moderately	86 (21.0%)	
Quite a bit	97 (23.7%)	
Extremely	73 (17.8%)	
Not applicable	44 (10.7%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Have a happy sex life		
Not at all	30 (7.3%)	297 (83.0%)
A little bit	31 (7.6%)	
Moderately	36 (8.8%)	
Quite a bit	68 (16.6%)	
Extremely	193 (47.1%)	
Not applicable	52 (12.7%)	

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Develop and maintain good relationships with friends and colleagues		
Not at all	92 (22.4%)	223 (55.5%)
A little bit	87 (21.2%)	
Moderately	96 (23.4%)	
Quite a bit	78 (19.0%)	
Extremely	49 (12.0%)	
Not applicable	8 (2.0%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Parent your children in the way you would like to		
Not at all	44 (10.7%)	110 (59.4%)
A little bit	31 (7.6%)	
Moderately	41 (10.0%)	
Quite a bit	34 (8.3%)	
Extremely	35 (8.5%)	
Not applicable	225 (54.9%)	
Rate the extent to which your chronic UTI symptoms have affected your ability to: Sleep well		
Not at all	31 (7.6%)	293 (71.5%)
A little bit	86 (21.0%)	
Moderately	101 (24.6%)	
Quite a bit	103 (25.1%)	
Extremely	89 (21.7%)	

Rating	Number (%) of participants giving each response	Number (%) of participants at least moderately impacted (excluding 'not applicable')
Rate the extent to which your chronic UTI symptoms have affected your ability to: Feel good about yourself		
Not at all	25 (6.1%)	314 (77.1%)
A little bit	68 (16.6%)	
Moderately	86 (21.0%)	
Quite a bit	102 (24.9%)	
Extremely	126 (30.7%)	
Not applicable	3 (0.7%)	
Overall, how much have your chronic UTI symptoms affected your quality-of-life?		
Not at all	1 (0.2%)	384 (93.7%)
A little bit	25 (6.1%)	
Moderately	73 (17.8%)	
Quite a bit	109 (26.6%)	
Extremely	202 (49.3%)	

ATTACHMENT 4: EXPERIENCES OF SEEKING HELP FOR CHRONIC UTI SYMPTOMS (DETAILED)

Table X: Experiences of seeking help for chronic UTI symptoms

Rating	Number (%) of participants giving each response	Number (%) of participants who 'agree' or 'strongly agree'
I have access to a healthcare professional who understands chronic UTI		
Strongly disagree	89 (21.7%)	201 (49.0%)
Disagree	73 (17.8%)	
Neither agree nor disagree	47 (11.5%)	
Agree	114 (27.8%)	
Strongly agree	87 (21.2%)	
It has been difficult to find a healthcare practitioner who understands and can treat my chronic UTI		
Strongly disagree	15 (3.6%)	339 (82.0%)
Disagree	26 (6.3%)	
Neither agree nor disagree	33 (8.0%)	
Agree	97 (23.6%)	
Strongly agree	239 (58.3%)	
I have felt that my symptoms have been dismissed or not believed by a healthcare professional		
Strongly disagree	15 (3.7%)	336 (81.9%)
Disagree	26 (6.3%)	
Neither agree nor disagree	33 (8.0%)	
Agree	97 (23.7%)	
Strongly agree	239 (58.3%)	

Rating	Number (%) of participants giving each response	Number (%) of participants who 'agree' or 'strongly agree'
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A healthcare professional has told me that my chronic UTI symptoms are caused by another medical condition

Strongly disagree	22 (5.4%)	273 (66.6%)
Disagree	51 (12.4%)	
Neither agree nor disagree	64 (15.6%)	
Agree	100 (24.4%)	
Strongly agree	173 (42.2%)	

A healthcare professional has told me that my chronic UTI symptoms are caused by stress or mental health, emotional or relationship problems

Strongly disagree	54 (13.2%)	167 (40.7%)
Disagree	116 (28.3%)	
Neither agree nor disagree	73 (17.8%)	
Agree	76 (18.5%)	
Strongly agree	91 (22.2%)	

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ABOUT CHRONIC UTI AUSTRALIA

Chronic UTI Australia came about after a small group of Australian women met online through their own experiences with chronic urinary tract infections (UTI).

By networking and sharing research information, resources and personal experiences over several years, it was decided this information and knowledge would be compiled and made available to others searching for answers to their own ongoing urinary tract symptoms.

In 2017, the Chronic UTI Australia website (www.chronicutiaustralia.org.au) came to life.

By 2018 it was evident that official advocacy was necessary, and an incorporated association was formed, followed by endorsement as a registered health promotions charity by the Australian Charities and Not-for-Profit Commission (ACNC) in 2019.

OUR MISSION

Our mission is to put urinary tract infection (UTI) on Australia's public health agenda by advocating for awareness, recognition, education, research, and improved testing and treatment for ALL forms of UTI.

Ultimately, we want to stop the underdiagnosis of UTI so that chronic UTI does not develop and cause needless suffering and destroy lives.

ABOUT THE AUTHOR

Deirdre Pinto has been involved with Chronic UTI Australia since its incorporation in 2018.

After completing a role with the Royal Commission into Victoria's Mental Health System in February 2021, Deirdre left a 30-year career as a Victorian Government policy analyst and program manager in health and community services areas. She currently works in service development at a mental health service in Melbourne.

Deirdre has been involved in advocacy for a rare neurological disease and has served as Secretary to the Board of Positive Women Victoria, a support and advocacy group for women living with HIV/AIDS. She also has a position with the consumer advisory group of Painaustralia.



Deirdre's experiences have led to her strong interest in the way people unite around marginalised or stigmatised health conditions – to support each other, share their experiences and knowledge, and advocate for changes that will improve the lives of others.


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