

‘Hearing Patient Voices’ – Chronic UTI patient survey: information statement

CHRONIC
UTI Australia Inc.



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Community
Underwriting

Who is conducting the survey, and why?

The survey is being conducted by Chronic UTI Australia (Incorporated), a volunteer-run national patient advocacy organisation focused on chronic urinary tract infection (UTI), a poorly recognised and mistreated health condition.

Our mission is to put 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.

In December 2019, we conducted a preliminary patient survey attracting 340 respondents. The results of that preliminary research have been used to help design the **'The Hearing Patient Voices'** survey.

'Hearing Patient Voices' will be based on a comprehensive questionnaire to ascertain 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).

'The Hearing Patient Voices' survey will provide robust data to measure the quality of life and broader impacts of chronic UTI. The survey data will be valuable from a research perspective, as chronic UTI is a neglected condition. The research is the first of its kind in Australia and there have been very few studies worldwide. Importantly, the survey will also allow Chronic UTI Australia to better understand our patient community and to provide targeted and actionable information for future advocacy work.

Overview of the survey

The **'Hearing Patient Voices'** survey will be an online survey of people who have been diagnosed with a chronic UTI, or who suspect they have a chronic UTI.

Chronic UTI Australia has received funding for the survey from Community Underwriting, <https://www.communityunderwriting.com.au/>. We have commissioned a professional survey research company, Websurvey, <https://www.websurvey.com.au/>, to help develop the survey and to host it via a secure online portal.

Participants will be recruited via social media, including online support groups and chat sites used by people with recurrent and chronic UTI, Chronic UTI Australia's subscriber database and other networks developed by Chronic UTI Australia since it was established in 2018.

People who register to participate will be emailed a link to an online questionnaire. This contains pre-coded questions about the person (their age, gender, place of residence etc); their UTI history, symptoms, treatment and use of health services; and both pre-coded and open-ended

(free text) questions about the impact of their condition on various life domains. The questionnaire includes a widely recognised and validated research tool for measuring health-related quality of life.

The time needed to complete the questionnaire will vary depending on the level of detail that participants choose to provide in response to the free-text questions. More detailed answers will result in a richer source of data for our analysis, so we are encouraging participants to set aside about half an hour to complete the survey. If it cannot be completed in one go, participants will be able to save their responses and return later to complete the survey.

Who is eligible to participate?

The survey will be completed by:

- 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 is expected that most participants will come from Australia, country of residence is not a barrier to participation. We will be actively recruiting from international networks and would welcome participation from residents of overseas countries. Unfortunately, the survey is limited to people who speak English.

What difference will my contribution make?

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. And the larger the sample size, the more credibility our research will have in the eyes of those who have the power to improve UTI testing and treatment for the benefit of current and future patients.

How will my confidentiality be protected?

Websurvey, the company we have commissioned to host the survey, will fully protect participants' confidentiality. Each person who registers for the survey will receive an email invitation that includes a link to the questionnaire that is unique to them, which helps guarantee data security.

When providing Chronic UTI Australia with data from the survey, Websurvey will not link the completed questionnaires to email addresses, so the identity of respondent will not be known to us (unless the respondent chooses to provide this information on the questionnaire) or any other party.

Participants can refuse to answer any question or reply to questions as briefly or as fully as they choose.

Most results of the study will be reported as group data only, and participant's individual information will not be identifiable in the report or in any other CUTIA materials where the survey results are reported. Our reporting may include quotes from respondents, but we will remove any references that could allow people to guess their identity. If we wish to use quotes or responses that could be linked to an individual, we will seek that person's written permission before including this information in our 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?

Deirdre Pinto, Secretary of Chronic UTI Australia, is leading the survey. Please contact Deirdre at deirdre@chronicutiaustralia.org.au or on +61 400 021 962 if you have any questions or if you would like more information about the project.

Once the report arising from 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.