Dear NHS Website Team

I am writing to the NHS website team to ask why the website does not give information or resources on Chronic UTI (CUTI), or at the very least, reference on the Interstitial Cystitis (IC) page concerns about the adequacy of testing. Because of inadequate testing, CUTI is often misdiagnosed as Interstitial Cystitis (IC) and as a result patients denied antibiotic treatment. Without treatment CUTI is entirely debilitating and ruins countless lives. There is reported evidence that the MSU culture misses up to 90% of patients with a CUTI. The urine dipstick misses 60% of CUTIs. For papers detailing the evidence please refer to <https://www.cutic.co.uk/wordpress/wp-content/uploads/2020/08/CUTIC-Medical-professionals-information-sheet-August-2020.01.pdf>

**[Insert very brief description of your CUTI diagnose to personalise, do not give lengthy history of illness eg. -** *I have a CUTI a diagnosis given by the Whittington NHS Trust, and I am under the care of their LUTS clinic. In February 2019 I had UTI symptoms post sex. My usual prophylactic antibiotic did not work and nor did the short courses provided by the GP. The symptoms remained and were unmanageable until being diagnosed with CUTI and given long term full dose antibiotic treatment.***]**

[**Insert experience of using** [**www.nhs.uk**](http://www.nhs.uk) **for help with CUTI diagnosis, eg**. - *After a few days I was worried why the symptoms were not clearing up and I turned to www.nhs.uk for help, I did not find it. The NHS website describes itself as ‘your complete guide to conditions, symptoms and treatments, including what to do and when to get help’. The page on UTIs did not help me, making no reference to persistent UTI symptoms. After a further search on the website I landed on the page ‘Interstitial cystitis’ and the more I read on the page the more scared I became. The website stated ‘it can have a significant impact on your lifestyle, work, emotional health and relationships’ and that it was a condition which could not be cured. Upon reading this I felt incredibly fearful, and the anxiety from reading this page stayed with me for months and months, even after receiving a diagnosis of CUTI from a urologist.***]**

Despite frequent mislabelling of CUTI patients with a diagnosis of IC, the NHS website IC page fails to reference the increasingly accepted position that current diagnostic testing for UTI is inadequate for patients with CUTI. The webpage states that IC can occur where ‘there is no obvious infection in the bladder’, it is a diagnosis of exclusion. However in October 2019 The British Association of Urological Surgeons (BAUS) issued a statement on CUTI and wrote ‘we agree that the classic technique/microbiological threshold to diagnose a UTI may be inadequate’. Yet despite the fact that tests used to exclude infection (and diagnose IC) are now being recognised as inadequate, the IC page makes no acknowledgement of this point and therefore does not support patients in pursuing an accurate diagnosis of their UTI symptoms, which may not be IC. Instead upon visiting IC webpage in search for help, many patients, are left terrified that they have IC with no cure.

Under the NHS Long Term Plan Personalised Care is a key priority; it should enable patients to have a voice and that voice be heard. Its implementation relies on patients being fully informed about their condition and how to manage it. The NHS website currently fails patients looking for information or advice on CUTI. The webpage for Interstitial Cystitis is up for review in August 2021 and so this is the perfect opportunity to listen to feedback from patients on what would be most helpful to include to ensure that patients battling for an accurate diagnosis for their bladder symptoms are supported in this process.

As an absolute minimum I propose that the IC page must recognise that IC is diagnosed on the basis of exclusion but that the diagnostic tools used to exclude bladder infection (which must be excluded for an IC diagnosis), for many patients are inaccurate and can lead to misdiagnosis. If patients can at least be informed of the pitfalls of diagnosis they can be empowered to discuss this further with their clinicians and be supported to find an accurate diagnosis of their bladder symptoms.

I would welcome the opportunity to be contacted further for input when the webpage is being reviewed. Please respond confirming that this email has been passed to the relevant team who will be undertaking the review of the IC webpage.

Yours sincerely

**[your name]**