

## **A Patient Survey on Nomenclature and Definition of Painful Bladder Syndrome/Interstitial Cystitis and the Nature of Urgency in PBS/IC Patients.**

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**Introduction and Objectives:** Recently much attention has been focused on new criteria and a new definition for interstitial cystitis. The new name “painful bladder syndrome” was proposed in 2004 with the ultimate aim of replacing the term IC. Additionally, there has recently been debate concerning use of the term ‘urgency’ for PBS/IC patients and whether this term should be reserved for overactive bladder/urgency incontinence patients. It has been controversially suggested that the urgent need to void experienced by PBS/IC patients is due to pain only and not to a specific urgency sensation. The aim of this international survey was to discover: 1) how patients would define PBS/IC and/or what they consider to be the most characteristic features; 2) whether, based on their own experience, they feel the sensation of urgency to be the same as pain, or a different sensation and also what happens if they cannot find a toilet immediately they feel an urgent need to void; 3) patients were also invited to express their views regarding the new name “painful bladder syndrome”.

**Method:** A survey with 3 open questions was sent to patients in different countries, placed on a website and distributed by several patient support groups in late 2005/beginning 2006. Use was made of open questions rather than ticking boxes so as to allow patients to provide background information rather than just answering yes or no.

**Results:** 78 patients responded from 12 different countries. 4 responders were male, 74 female. Ages varied from 22 to 83 years. With regard to a definition of IC, patients felt that emphasis should be paid to pain, but should include urgency and frequency. 53 (67.9%) felt that urgency sensation and pain are completely different, 13 (16.7%) that pain and urgency are the same, while the remainder expressed no opinion. They stated that pain and urgency would sometimes occur simultaneously, sometimes pain without the urgency and sometimes urgency without the pain. Although the survey did not ask where the urgency sensation was localized, 3 responders volunteered the information that they felt it to be in the urethra. Concerning what happened if they could not find a toilet, the responses were very similar: they felt nauseous, an urge to vomit, began to sweat, go hot and cold, flushed, dizzy, faint, shaky, panic attacks, increasing pain, while many experienced difficulty in starting urination if they had to wait to reach a toilet. 6 responders said that they would experience involuntary leakage. Several responders emphasized that they would never place themselves in this position and would not leave the house if there was a risk of not finding a toilet. Concerning the name “painful bladder syndrome”: 30 (38.5%) were reluctant to abandon the name “interstitial cystitis”, 24 (30.8%) were willing to accept “painful bladder syndrome”, 5 (6.4%) were willing with reservations, while 19 (24.3%) either expressed no opinion or stated that they did not care what it is called as long as they received treatment. Many alternative names were offered.

**Conclusions:** When drawing up a new definition of PBS/IC, account should be taken of urgency/frequency as well as pain. It is also recommended that a study be carried out into the nature, location and mechanism of urgency in PBS/IC patients since better insight could facilitate treatment. There was no clear conclusion regarding the name. The responses to the open questions produced valuable insight into the impact of PBS/IC on patients’ lives.