

# Report on A Patient Survey on Nomenclature and Definition of Painful Bladder Syndrome/Interstitial Cystitis and the Nature of Urgency in PBS/IC Patients, 2005-2006

## “I stay at home and miss out on life”

*With sincere thanks to all patients who participated in this survey in the hope that this would help other patients.*

Recently much attention has been focused on new criteria and a new definition for IC. The name “painful bladder syndrome” was proposed in 2004 with the ultimate aim of replacing the term IC. There has also been considerable debate – particularly with the International Continence Society - concerning use of the term ‘urgency’ for IC patients and whether or not this term should be exclusively reserved for overactive bladder and urgency incontinence patients. It has been suggested that the urgent need to void experienced by IC patients is due to pain only and not to any specific urgency (pain) sensation. The aim of this small 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 invited to express their views regarding the new name “painful bladder syndrome”.

A survey with 3 open questions was sent to patients at the end of 2005 and 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. These detailed responses produced valuable insight into the devastating impact of IC on patients’ lives.

78 patients responded from 12 different countries. 4 male, 74 female. Ages from 22 to 83 years. Symptoms varied from mild to very severe. And this aspect proved to be important.

### **Question: How would you define PBS/IC?**

Almost all responders felt that the definition rests on three main symptoms:

**pain, urgency and frequency.**

Many felt that the **urgency/frequency** had the most traumatic impact on their life and that this should most definitely not be omitted in any definition.

**Conclusion:** The definition should include equal emphasis on pain, urgency and frequency.

### **Question: Is urgency the same as pain?:**

13 (16.6%) stated that urgency and pain are the same  
53 (67.9%) stated that urgency is a completely different sensation to pain  
12 (15.3%) expressed no opinion.

Patients 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 base of the bladder or urethra, while the pain in contrast was felt everywhere in and around the bladder.

A typical comment was: "Pain is present the whole time, the urgency sensation begins with just a couple of mls touching the bladder."

The responders who felt that pain and urgency are the same sensation tended to be those with severe pain predominating.

**Conclusion:** Urgency is a separate (pain) sensation to other pain sensations. Urgency in IC is different to urgency in overactive bladder and urgency incontinence.

**Hypothesis:** constant severe pain may mask separate urgency sensations.

**Action point:** It is desirable for an in-depth scientific study to be carried out into the nature, location and cause of urgency sensation in IC patients. The study population should include a cross-section of patients from mild to severe and specifically should not comprise all severe patients. Insight could lead to improved treatment.

**Question: What happens if you can't find a toilet immediately?:**

The responses to this were very similar:

They felt nauseous, had an urge to vomit, began to sweat, go hot and cold, pain sensation over the whole body, flushed, bloated, faint, shaky, dizzy, suffocating sensation, panic, while many experienced increasing extreme pain and **difficulty in starting urination** if they had to wait to reach a toilet. Some reported that they might go into complete retention and have to self-catheterize in such a situation.

6 patients reported that they would leak (ages 43-81 years).

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.

**Question: What are your views on the name Painful Bladder Syndrome?**

In favour: 24 (30.7%)

Possibly in favour (with reservations): 5 (6.41%)

Against: 30 (38.5%)

No opinion: 19 (24.4%)

Those in favour felt that it would at least stop other people thinking they had an infection or asking "IC: what on earth's that?". "People would understand what you mean".

Some of those possibly in favour but with reservations felt that PBS was a good umbrella term but further classification of patients was needed beneath this umbrella. Others felt that PBS is a very inadequate name, but on the other hand better than the confusion caused by IC.

Those against (majority) stated that they were reluctant to abandon the name interstitial cystitis because:

PBS is too vague, doesn't cover the symptoms as experienced by the patients, not strong enough, fails to convey the huge and intense impact of urgency/frequency.

"If we have a new name it has to be better than this".

"IC is the better name for the moment until research produces new insights".

Some felt that the broad term would lead to more confusion.

**Conclusion:** Those with pain predominating as a symptom tended to favour PBS. Those in whom urgency/frequency predominated found the name PBS inadequate.

Many alternative names were offered.

Some of the patients had received an amazing variety of names as a diagnosis, varying from irritable bladder to diffused inflammatory interstitial cystitis.

**Poignant quotes:**

*"I was not diagnosed as definite IC because my physician could not see ulcers"*

*"My IC causes me depression and anxiety"*

*"IC makes normal life almost impossible"*

*"I feel completely disabled"*

*"I often sit on the toilet and cry"*

*"Tears come to my eyes with the pain"*

*"I have urinated behind many bushes along the highway"*

*"If I travel by car, I take a bedpan with me"*

*"I never put myself in the position of not being able to find a toilet"*

*"When you are out of your home, the whereabouts of toilets is paramount"*

***"I stay at home and miss out on life"***

*Jane M. Meijlink*

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