

A WEB BASED SURVEY ON CURRENT AND PAST TREATMENTS AND OUTCOME FOR PEOPLE LIVING WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME

This is a study by group of researchers from the University of Southampton on the treatment and outcome for people living with Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS). Confidentiality of your data would be maintained throughout the study period and beyond. Participation in this survey is voluntary and participants are free to withdraw at any point of the study. Data obtained from this survey will be treated with the highest level of confidentiality by inputting into an excel spreadsheet which would be password-protected, accessible only to the researchers. The survey takes approximately 20 minutes to complete.

The survey has 8 parts viz:

1. Health history (12-questions)
2. Treatment (5-short questions)
3. Pelvic pain and urgency/frequency Index (12-questions)
4. The O'Leary/Sant Index Symptom Index (4- questions)
5. The O'Leary/Sant Problem Index (4- questions)
6. The Kings Health Quality of Life Index (10-questions)
7. The Brief Illness Perception Index (9-questions)
8. Demographic Information (5-questions)

Instructions for completing the survey

1. Your consent for taking part in this survey will be indicated by ticking the box provided. Thereafter, if you wish to continue you press the next button.
2. Please answer each question by ticking at the appropriate box. You should answer the correct option by ticking at the appropriate box for most question. However, where multiple answers are required it will be clearly be specified by the side of the question in italics
3. In some instances, an open question will be asked where a participant is asked to answer in his/her own words. In such circumstances, a free text column would be highlighted and the participant asked to make an appropriate comment.
4. Proceed through the survey using the 'save and continue' button at the end of each page
5. The 'save and quit' button will ensure your responses are saved and you can continue completing the survey at another time by following the instructions given.
6. When you have finished the survey, please click the 'save and finish' button at the end of the survey.

CONSENT

1. I have read and understood the information sheet and have had the opportunity to ask questions about the study
2. I agree to take part in this research project and agree for my data to be used for the purpose of this study
3. I understand my participation is voluntary and I may withdraw (at any time) for reason without my participation rights being affected

4. I understand that I will not be directly identified in any reports of the research
5. I understand should I withdraw from the study then the information collected about me up to this point may still be used for the purpose of achieving the objectives of the study only.
6. I understand that certain category information i.e. health data, will be collected about me to achieve the objectives of the study.

Many thanks for your co-operation, We would be delighted if you could complete this survey by (07/03/19)

For further information, kindly contact:

1. Kamaluddeen Garba (K.Garba@soton.ac.uk)
PhD student, University of Southampton
2. Dr Brian Birch (B.Birch@soton.ac.uk)
Supervisor, University of Southampton
3. Prof Bashir Lwaleed (Bashir@soton.ac.uk)
Supervisor, University of Southampton