HOW TO FOLLOW AND UNDERSTAND RESEARCH

A GUIDE FOR IC/BPS PATIENT ADVOCATES, PATIENT ORGANISATIONS AND PATIENTS

It is important for patient organisations and their representatives to be informed about national and international developments in the field of scientific research, treatments and any changes in diagnostic and treatment guidelines related to interstitial cystitis/bladder pain syndrome (IC/BPS).

Having a general overview of current research enables patient advocates and patient organisations to:

- Provide reliable, up-to-date information for websites, newsletters, and educational materials
- Support members in improving their health literacy and understanding of IC/BPS
- Communicate more effectively with healthcare professionals and researchers

WHERE IS IC/BPS RESEARCH PUBLISHED?

New research findings, developments, and review articles are published primarily in **scientific journals**. For IC/BPS, these are most often journals focused on **Urology**, including:

- *Journal of Urology* (American Urological Association, AUA)
- *European Urology* (European Association of Urology, EAU)
- *BJU International (BJUI)*
- *Urology* (also known as *The Gold Journal*)
- *Neurourology and Urodynamics*
- *Continence* (International Continence Society)
- *International Journal of Urology*
- *Current Opinion in Urology*
- *Nature Reviews Urology*
- *Bladder*
- *World Journal of Urology*
- *Canadian Urological Association Journal*

A broader overview of leading journals can be found here:
Best Medicine Journals Ranking for Urology | Research.com

Research related to IC/BPS may also appear in **pain-focused journals**, for example:

- *Pain* (International Association for the Study of Pain, IASP)

Most major scientific journals publish in **English**, although many countries and national medical societies also publish journals in their own languages.

OPEN ACCESS ARTICLES

In the past, reading full scientific articles often required society membership or payment of a substantial fee. Today, an increasing number of articles are published as open access, meaning that the full text can be read online free of charge.
When an article is not open access:

- The abstract is usually available for free.
- The abstract is a short summary describing the introduction, methods, results, and conclusions.
- The full article includes detailed methods, references, figures, tables, and acknowledgements.

USING PUBMED

PubMed is a free online database maintained by the U.S. National Library of Medicine (NLM) and the National Institutes of Health (NIH). It provides access to millions of references and abstracts from biomedical and life sciences literature, primarily from the MEDLINE database.

PubMed is particularly useful for patient advocates who want to stay informed about current medical research and develop accurate patient information materials.
Website: https://pubmed.ncbi.nlm.nih.gov/

How to search PubMed

1. Enter keywords into the search bar, for example:
   interstitial cystitis, *bladder pain syndrome*, *Hunner lesion*
2. A list of article references will appear
3. Use **"Sort by" → "Most recent"** to find the latest publications

Understanding citations

An article reference (citation) usually includes:

- Author(s)
- Article title
- Publication date
- Journal name
- Page numbers or DOI (digital object identifier)
- Information on whether the full text is freely available (open access)

Clicking on a citation opens the **abstract**. On the right-hand side, you may find links to:

- The journal website
- The full article (if open access)

Some journals also provide **lay summaries** written specifically for patients.

CAN'T UNDERSTAND THE ABSTRACT?

If the abstract is difficult to understand, you can:

- Copy and paste the text into a plain-language AI tool (such as ChatGPT).
- Ask AI for a simpler explanation or a translation into your own language.

PEER REVIEW

Most scientific articles are peer-reviewed before publication. This means:

- The authors submit their manuscript to a journal.
- Independent experts in the same field ("peers") review the work.
- Reviewers assess the importance of the research question, study design, accuracy of results, and validity of conclusions.
- Authors may be asked to revise their manuscript before acceptance.

Only after successfully completing this process is the article published.
Note: In some cases, journal editors invite experienced patient advocates to participate in the peer-review process.

COPYRIGHT AND PLAGIARISM

Published journal articles are protected by **copyright**. This prevents others from using the work without proper acknowledgement.

- Copying text, ideas, or results without citation is known as **plagiarism.**
- Plagiarism may be intentional (copying on purpose) or unintentional (forgetting to cite sources or paraphrasing too closely).
- When quoting or referring to an article, always provide the full citation/reference (as listed on PubMed).
- Articles that are not open access must not be shared or distributed without permission.

OTHER USEFUL INFORMATION SOURCES

MedlinePlus provides reliable, easy-to-read health information for patients, families, and caregivers. It is a service of the National Library of Medicine (NLM), part of the NIH:
https://medlineplus.gov/

StatPearls

https://www.statpearls.com
StatPearls is an educational resource primarily designed for healthcare professionals and students. However, it can also be useful for patient advocates who want in-depth information on specific diseases, disorders, treatments, procedures, and clinical concepts.

PATIENT EXPERTS IN RESEARCH GROUPS

Today, **expert patients** are increasingly involved in research projects as advisory partners. Their role is to:

- Provide the patient perspective
- Ensure research reflects real-life symptoms and priorities
- Help researchers focus on outcomes that matter most to patients

To contribute effectively, patient representatives need a basic understanding of:

- Different types of research
- How and where research is published
- Key journals in the IC/BPS field
- How to search for new research

UNDERSTANDING STUDIES AND CLINICAL TRIALS

Several websites provide clear explanations of clinical research and trials, including:
https://clinicaltrials.gov/study-basics/learn-about-studies

https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics

https://www.uclh.nhs.uk/our-services/find-service/cancer-services/cancer-clinical-trials/what-types-clinical-trial-are-there

These websites also explain about participation by patients as study subjects in clinical trials which evaluate the effects of new potential treatments.

SOME BASIC TERMINOLOGY

(See also: Glossary of Research Terminology for Patient Advocates)

Main Categories of Medical Research

- **Basic Research:** Fundamental, laboratory-based research exploring biological processes and disease mechanisms.
- **Translational Research:** Connects basic science to clinical practice, moving discoveries from the laboratory to patient care ("bench to bedside").
- **Clinical Research:**
- Research involving humans to test interventions or observe health and disease, including:
    - Treatment trials
    - Prevention trials
    - Screening trials
    - Diagnostic research
- **Epidemiological Research:** Studies disease patterns, causes, and outcomes in populations, often using observational methods.

CLINICAL RESEARCH IN MORE DETAIL

Clinical research directly concerns patients, as it involves human participation and aims to improve understanding of disease, treatment effectiveness, and safety.

Types of Clinical Research

- **Clinical Trials (Interventional Studies)**
  Formal studies in which participants receive specific interventions.
- **Observational Studies**
  Researchers collect or analyse existing data without assigning interventions.
    - *Cohort studies*: Follow groups over time
    - *Case–control studies*: Compare patients with and without a disease
    - *Patient registries*: Organised collections of patient-provided data
- **Randomised Controlled Trials (RCTs)**
  The gold standard for evaluating treatment effectiveness.
- **Qualitative Research**
  Explores patient experiences and perspectives, often through interviews.
- **Case Reports and Case Series**
  Detailed descriptions of individual patients or small groups, especially useful for rare conditions.
- **Systematic Reviews and Meta-Analyses**
  Combine results from multiple studies to provide stronger, evidence-based conclusions.

REFERENCES:

Clinical Research Basics

- **ClinicalTrials.gov — Glossary of Terms**
  https://clinicaltrials.gov/study-basics/glossary?utm_source=chatgpt.com

- **ClinicalTrials.gov — Learn About Studies**
  https://clinicaltrials.gov/study-basics/learn-about-studies?utm_source=chatgpt.com
- **NIH Glossary of Common Clinical Research Terms**
  https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms?utm_source=chatgpt.com

Patient Voice & Engagement

- **FDA Patient-Focused Drug Development Guidance Series**
  https://www.fda.gov/drugs/development-approval-process-drugs/fda-patient-focused-drug-development-guidance-series-enhancing-incorporation-patients-voice-medical?utm_source=chatgpt.com
- **FDA Patient-Focused Drug Development Program Overview**
  https://www.fda.gov/drugs/development-approval-process-drugs/cder-patient-focused-drug-development?utm_source=chatgpt.com

Patient-Friendly Language

- **FDA Patient-Friendly Language for Clinical Trials**
  https://www.fda.gov/about-fda/oncology-center-excellence/patient-friendly-language-cancer-clinical-trials?utm_source=chatgpt.com
- **NCI Dictionary of Cancer Terms – Clinical Trial**
  https://www.cancer.gov/publications/dictionaries/cancer-terms/def/clinical-trial?utm_source=chatgpt.com

Optional Overview Resources

- **Wikipedia — Clinical Trial**
  https://en.wikipedia.org/wiki/Clinical_trial?utm_source=chatgpt.com
- **Wikipedia — Inclusion and Exclusion Criteria**
  https://en.wikipedia.org/wiki/Inclusion_and_exclusion_criteria?utm_source=chatgpt.com

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