

# Reading and participating in research about Long COVID



**LONG COVID ESSENTIALS: A series by [The Sick Times](#) & [Long COVID Justice](#)**

Medical providers might not know about the latest Long COVID research. Updating medical practices based on research takes a long time: [up to 25 years](#). So, people with chronic diseases often [find online information](#) to advocate for their own care. You can read studies to learn about potential treatments, then [bring them to doctor's appointments](#).

## \* Where to find scientific papers

- Resources managed by the National Library of Medicine:
  - [MedlinePlus: Long COVID fact sheet](#), links to recent research and clinical trials.
  - [PubMed Central](#): free biomedical research papers
- [Cochrane Rehabilitation](#): reviews of scientific evidence about potential treatments
- Academic search engines/databases: [Google Scholar](#), [ScienceDirect](#), or [PubMed](#)
  - A library card might help you get access to paywalled research.
- [EurekAlert!](#): press releases about research from universities, research institutes, government agencies
- Online support groups/forums and email newsletters
  - [Long Covid Weekly](#)
  - [Body Politic's Community Support Group List](#)
  - [The Sick Times' newsletter](#)



## \* Determining the type of care you need

Understand the “big picture” of a paper before going into specifics. Papers are often broken down into specific sections. You might read them in this order:

- **Abstract and title:** An overview of the study and its findings, summarizing the rest of the paper.
- **Introduction:** Identify the research question and how it adds to existing knowledge.
- **Conclusion/discussion:** These may be the last sections of the paper. They explain the results of the study, how findings relate to other research, challenges for this study, and potential next steps. This will give you context for the details in the other sections.
- **Results and methods:** How data were collected and analyzed. Pay attention to:
  - Horizontal and vertical scales of graphs
  - Symbols and color schemes in graphs
  - Statistical analyses and sample sizes (who and how many people were in the study, and what data was evaluated?)
- **Acknowledgements:** Look at funding sources and potential conflicts of interest.
- **References:** Find relevant papers that may give you additional information or perspectives.

## \* Understanding peer-reviewed paper vs. pre-prints

- **Peer-reviewed publication:** Papers are sent to researchers who work in this area but who were not part of the study team. They give feedback and criticism used to recommend further edits, in order for the study to be approved and published.
  - This does *not* involve external replication of results.
- **Preprint:** The paper has not (or not yet) gone through peer review. These are generally published on arxiv/bioarxiv/medrxiv. The results may be considered less definite or more preliminary.



## \* Resources:

- [Rules for reading a scientific paper](#) – *PLoS Computational Biology*
- [How to read a scientific paper](#) – Research4Life
- [How to read and review a scientific journal article](#) – Duke University

## \* Participating in research

If you join in a clinical trial, you may get early access to a potential treatment. Anyone who signs up for a trial will be given an informed consent form, which will detail what the trial is studying, what is required from participants, and possible risks and benefits.

If a study involves one or more treatments, they will be described in the consent form. Some trials compare treatments to a placebo, which is similar to the treatment but does not contain the active ingredients. Look at the study's name and description, eligibility criteria, who funded the study, potential risks of the treatment, and where the trial is being held.

### Finding relevant trials:

- [ClinicalTrials.gov](#) – study records in the U.S. and over 200 countries.
- [Long COVID Studies](#) – patient-friendly database of Long COVID-related trials
- [Mayo Clinic's clinical trial finder](#)
- [Solve Together](#) – patient-developed platform that matches patients with trials

**FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE:**  
[tiny.cc/LCE](https://tiny.cc/LCE) or scan the QR code with your phone camera.



**QUESTIONS?** [connect@s4hi.org](mailto:connect@s4hi.org)

*This series was designed by people living with Long COVID and associated diseases. Each resource sheet has been reviewed by patient and medical experts. This is an informational resource, not medical advice. Publication date: 12/13/2024.*