How to Guide for Patient Data Entry – Infectious Diseases and Long COVID

Do you have a disease or condition that has been treated with a drug in a new way (e.g., drug repurposing)?

We need to hear from you!

Contribute your experience to the CURE ID patient treatment registry to help the scientific, medical, and patient communities learn about the effectiveness of these treatments.

How does it work?

First, fill out the quick registration:

1. **Visit https://cure.ncats.io or download the "CURE ID" mobile app** from the Apple App or Google Play Store
2. **Register (sign-up)** on the CURE ID mobile app or website as a patient with your email and a password or sign-in using social sign-in features of Google, Facebook, X (formerly Twitter), etc.
3. During the registration, you have the option to provide your first and last name, but you do not have to do so (you can leave it blank). Even if you do provide it in the registration process, your name will not be shown publicly if you submit a case.
4. **Check your email** (including your spam filter) **for an email confirming your account and click the link in the email to verify your account.**

Once you have registered:

1. You may then **explore the cases that have been entered** so far by other patients, doctors, and researchers, including those from the published literature.
2. **When you are ready to report your own experience, select "Create" from the main menu and choose create a "Case Report"**
3. You will be asked to read a short, **informed consent form** and check a box stating that you understand that your case is being collected for research purposes as part of a treatment registry and that you agree to contribute your information.
4. You will then **enter the disease** you are entering a case on, to ensure you are taken to the correct form. *

   (*if you are entering a case of Long COVID or MPOX and you clicked on it from the banner on the homepage, you will skip this step)

5. **Answer the questions in the case report form.**

   Note: Many of the questions are optional, so if you don't know the answer, feel free to skip the question. **Please be sure that you do at least fill in the details of the disease, drug, and outcome, for your case to be accepted. Remember to not include any personally identifiable information** in the free text boxes (e.g., don't include specific dates, locations, names, etc.). Any identifiers that are inadvertently included will be removed by CURE ID clinical curators.
   a. For most people, the case report form will take ~5-20 minutes (some with more complicated disease and treatment histories will take longer – the Long COVID survey may take 20-45 minutes)
   b. **You always have the option to save and come back to your report at a later time, if you feel like you need to take a break. Just click "save and exit" from the top right of your screen. You can then access your case under "Account – Activities - Case Reports"**
   c. At the end of the case report form, you have an option to upload pictures of your condition (e.g., of the blisters before and after treatment, or of test results).
      i. Please upload images, making sure that they don't contain any personally identifiable information (e.g., your face, your name, dates, markings on skin like tattoos or scars which may allow viewers to recognize you, medical records numbers, etc.).
      ii. Any identifiable information should be covered with a black box before your image is uploaded to the CURE ID site.
   d. **Note that all other users will be able to see all of the information you entered as part of the case. They will, however, not see your name as the author of the report.** Remember that the information you include in the case report form might include information you find sensitive or would prefer not to share (e.g., past medical history, sex and gender identity questions, medications, etc.). Please do not share any information that you would not be comfortable with others seeing.
   e. **When you're all set, hit submit! (Note: If you save but do not submit, your case will not be visible in the platform and will not contribute to data that is analyzed, so please be sure you submit your case – you can always go in and edit it later)**

6. **Your case will now go to CURE ID/CDRC staff for review**
   a. They will make sure it doesn't contain any information that could compromise your privacy.
   b. If they have any questions about the information you entered, they may email to ask follow-up questions (this will come from curesupport@nih.gov).
   c. Once your case has been reviewed, if it meets the requirements for posting, it will be accepted and will become visible on the CURE ID platform and will be added to other cases for users to explore.

Are you a Long COVID patient and have more questions? Check out our FAQ document here:

https://cure.ncats.io/assets/faq-long-covid.pdf

Screening Questions

1. Are you 18 years of age or older?

○ Yes

○ No

2. Have you been diagnosed with or experienced symptoms of Long COVID (also called PASC, Long Haulers, Post-COVID, and Long-Haul COVID) for at least 12 weeks since your original acute COVID-19 infection?
Note: If you are completing this form on behalf of someone else, wherever the case report form states 'you', please answer as if the person with the condition was completing the form.

○ Yes

○ I am completing this survey on behalf of someone else (e.g., a loved one or patient) who has Long COVID

○ No

3. Are you taking any prescription medications, over the counter medications, or vitamins/supplements/nutraceuticals that you feel have had an impact on your disease/symptoms?

○ Yes

○ No

The only questions that must be answered for the case to be accepted are the disease, the medications, and the treatment outcome.

Please feel free to skip any other questions you choose or which you don't know how to answer.

You can save and return to this survey at any time, so it does not need to be completed in one sitting. Please take breaks throughout as needed.

FAQs for CURE ID Long COVID Treatment Survey

CANCEL   CONTINUE