

Five equity challenges and possible solutions in Long COVID clinical trials

Dr. Letícia Soares

Co-lead and patient-researcher at the Patient-Led Research Collaborative

leticia@patientledresearch.com

RECOVER-TLC Workshop

September 9, 2025

Long COVID disproportionately impacts marginalized people

Due to structural racism, marginalized and historically disenfranchised populations are at higher risk of COVID infections, and thus of Long COVID

- The prevalence of Long COVID is higher among non-white people, people without a college degree, and LGBTQ people (Cohen, J and van der Meulen Rodgers, Y. 2023. Int J Equity Health 22, 261, <https://www.census.gov/library/stories/2023/05/long-covid-19-symptoms-reported.html>).
- Socially disadvantaged populations are 2.5x more likely to report Long COVID (Xiang, J et al. 2025. BMC Medicine 23, 207).

Long COVID biomedical research has an equity issue



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Addressing Trial Inequities: for today and tomorrow

- Inequity in Long COVID research is a major barrier to finding effective treatments.
- **Pervasive inequity biases data.** Biased data leads to analytical issues:
 - Trial results cannot be generalized beyond the sampled population
- Addressing disparities in research participation will **ensure the data collected reflects the experiences of the most impacted populations.**

Challenges & Possible Solutions To

1. Demographic Bias
2. Regional Bias
3. Demographic & Regional Bias in PRO Design
4. Clinical Trial Accessibility
5. Treatment Accessibility & Scalability

1st Challenge: Demographic Bias



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1st Challenge - Demographic Bias

- The **demographics** of nearly every Long COVID study are **overwhelmingly white**.
 - Lack of diversity among researchers in the field, including patient-researchers
 - Barriers to participation in research
 - Barriers to healthcare access and Long COVID diagnosis and treatment
- clinicaltrials.gov → completed drug interventional clinical trial with results

11

Completed
trials

9

Reported race
data

6

Trials had 80% or more
white participants

3

Trials had 69–74% white
participants

Possible solutions:

- **Fix the pipeline by addressing disparities in access to diagnosis and treatment.** Marginalized patients are less likely to have Long COVID awareness, receive a diagnosis and thus have access to treatments, including clinical trial opportunities:
 - African Americans and Latinx are over **3 times more likely** to have **poor awareness** of Long COVID (Rodriguez, M et al. 2025. Ann Emer Med, 85(3), 230–239)
 - African Americans are **underrepresented in EHR databases** of individuals who received an **official Long COVID diagnosis** (Reese JT et al. 2023. EBioMedicine. 2023; 87:104413)

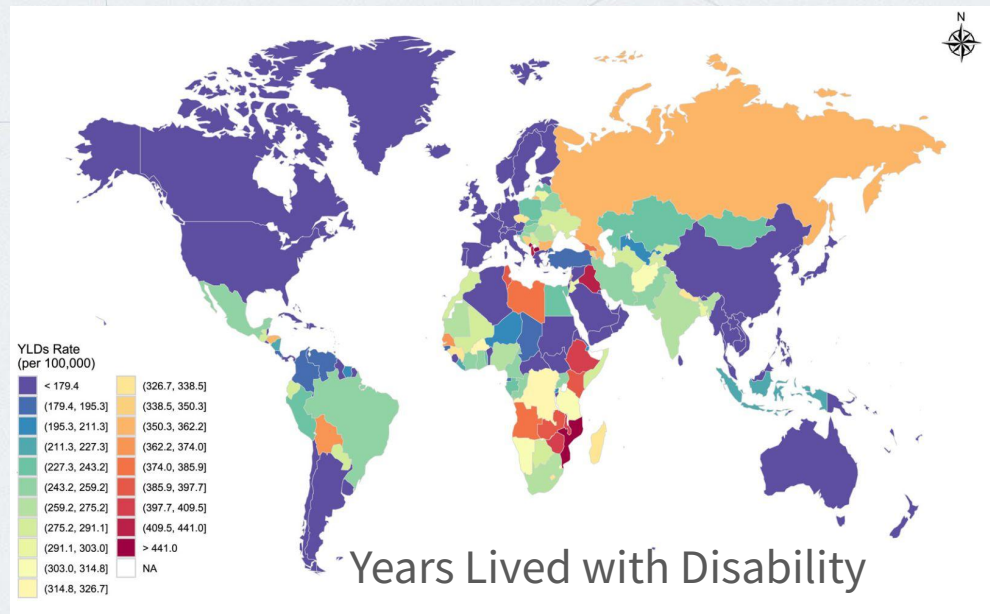
Possible solutions

- Leverage the **expertise** of marginalized patient researchers **to diversify enrollment strategies.**
- Select **enrollment targets** that correspond to the demographics of people affected by Long COVID.
- **Think intersectionality:** treatment effectiveness must be evaluated while controlling for crossover of factors such as sex and race.
- Avoid reducing marginalized patient populations to “lack of statistical power”: plan accordingly so that there’s enough **statistical power for group analyses.**

2nd Challenge: Regional Bias

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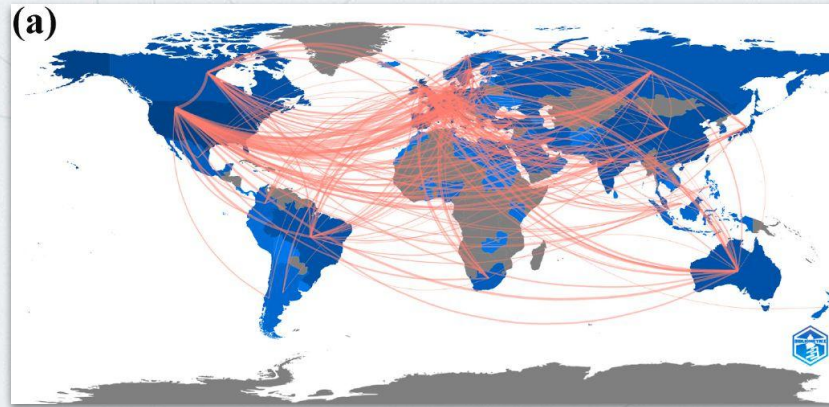
- **Global disparities in risk:** Higher risk of Long COVID in **low income countries**, and among Arab and North African populations (Hermans LE et al. 2025 BMJ Global Health, 10:e017126)
- **Higher burden of Years Lived with Disability** in Sub-Saharan Africa, parts of South Asia, Eastern Europe, and some LMICs (e.g. Kenya).



Shan, D et al. 2025. Med Research: 1–21.

2nd Challenge: Regional Bias

Most studies are in patient populations from high and upper middle income countries



US and Europe produce contribute the most to Long COVID research, and have the strongest collaborative ties. (Lai, Z et al. 2024. Heliyon, 10(2), e24053)

Possible solutions:

- Multi-country clinical trials offer a powerful opportunity for knowledge exchange and bidirectional capacity building in Long COVID research.
- **Leverage the expertise** of researchers and patients from **LMICs**.
- Design trials that can **support collaboration among LMICs**.
- **Data transparency:** report results by country—do not fail to collect, report and analyze race and ethnicity data by country.

3rd Challenge: Demographic and regional bias in PRO design

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- The few patient reported outcomes (**PROs**) that are specific for Long COVID have been **developed and validated** in patient population samples that are predominantly **white and from a few high-income countries**.
- Without dedicated effort and resources to develop, optimize, and validate patient reported outcomes in diverse patient populations, **we risk perpetuating health inequities and exacerbating health disparities**.

Possible solutions:

- Meaningful international collaboration involving researchers and patients from LMICs.
- Linguistic and cross-cultural content validity of PROs.
- Psychometric performance evaluations of patient reported outcomes that control for social and environmental determinants health.

4th Challenge: Clinical Trial Accessibility



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4th Challenge: clinical trial accessibility

Participation in clinical trials are largely inaccessible for marginalized patient populations. Barriers include:

- Underrepresentation racialized and minoritized researchers conducting clinical trial research
- Inadequate funding for clinical trials in geographical areas serving minority and marginalized populations
- Low awareness and education among research staff about which underrepresented groups to target for recruitment
- Lack of or suboptimal strategies to reaching out to marginalized populations

Possible solutions

- Investment in **career opportunities for racialized and minoritized researchers.**
- Investment in training of **patient advocates** and **clinical trial navigators for Long COVID.**
- **Make it easy** for patients to obtain **documentations** necessary to apply for **paid time off** and other protections during clinical trial participation.
- **Address logistic barriers** for participation such as transportation and child care provision.

5th Challenge: Treatment accessibility and scalability



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5th Challenge: Treatment accessibility and scalability

Long COVID is a global public health crisis – approved pharmacological treatments must be scalable and accessible to all patient populations. The ideal drug treatment should:

- Have **low cost** to end consumer
- Be **globally accessible**
- Be **swiftly deployed**/have high scalability

Possible solutions:

- Researching and trialing of **repurposed drugs**.
- Repurposing involves:
 - **Lower costs** than drug development from scratch
 - A **faster route to market**—and the resulting earlier return on investment
- We need policies that **prioritize** and set **designated funding** to research and clinical trials **testing repurposed drugs**, and specific funding opportunities for **investigatory initiated clinical trial research** involving drug repurposing.

CURE ID

Long COVID Patients, Care Partners, or Healthcare Providers

Learn how YOUR experience may help to inform future research, identify promising treatments, or treatments that are ineffective or harmful.

These treatment experiences may also inform the drugs studied in clinical trials.



About CURE ID

Working with patient and clinician advocacy groups, the FDA and NIH established CURE ID, an online treatment registry that allows Patients, Care Partners, or Healthcare Providers to share their real-world experiences using existing drugs in new ways, and explore what others have tried.



Study Partners



Project URL

<https://cure.ncats.io/pilot-overview/long-covid>



Thank you!

leticia@patientledresearch.com

