Urgent Letter from Patient Representatives and Researchers to RECOVER
Re: the misuse of the Long Covid Research Index (LCRI)
July 2026

To RECOVER leadership and consortium:

We are writing to request urgent action on the use of the adult Long COVID Research Index in Long COVID research, particularly in RECOVER-associated proposals and manuscripts.

We write as patient representatives, researchers, and individuals living with Long COVID (LC) to request urgent action about the growing misapplication of the RECOVER-Adult Long COVID Research Index (LCRI). While we acknowledge the scientific effort behind this index and the value of attempting to create an exploratory research classification tool, we are deeply alarmed by the trajectory toward its use as a measure of Long COVID classification, severity, recovery, resolution, worsening, improvement, or symptom burden. The index is not designed for this purpose, and its use in this way is both scientifically indefensible and actively harmful to the patient community it is meant to serve.

Despite this, in our roles as RECOVER representatives and researchers we regularly continue to see proposals, papers, and research studies led and run by RECOVER researchers that use the LCRI for these purposes. Several have already been published, with dozens in the RECOVER pipeline.[1,2,3,4,5] There has also been communication from RECOVER to the public that the LCRI can be used in this way - including from co-PI Dr. Horwitz and LCRI lead author Dr. Thaweethai.[6] This not only risks RECOVER's reputation – it deeply lowers the quality of Long COVID research, propagates inaccurate narratives to the general public which causes direct harm to support and clinical care, and misses the opportunity to provide useful findings that further the field.

Misuse of the LCRI

The language of the 2024 LCRI paper is explicit: "The index is not designed for clinical diagnosis." This is a foundational limitation - not a minor caveat. This caveat has been emphasized since the June 2023 guidance that accompanied the initial publication: "Insurers, disability agencies, and/or doctors should not use findings from this study to clinically define or rule out Long COVID."

The LCRI's symptom weightings reflect population-level statistical associations, not clinical severity. It has not been validated against an independent clinical or patient standard of Long

[1] https://www.nature.com/articles/s41467-025-65239-4
[2] https://www.acpjournals.org/doi/10.7326/ANNALS-24-01971
[3] https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.70043
[4] https://journals.lww.com/greenjournal/abstract/2026/03000/long_covid_after_acquisition_of_the_omicron.15.aspx
[5] https://www.acpjournals.org/doi/10.7326/ANNALS-25-05275
[6] https://www.washingtonpost.com/wellness/2023/05/25/long-covid-symptoms-recover-study/

COVID diagnosis with ground truth labels. It has also not been validated against illness severity, improvement/worsening, recovery, or symptom/functional burden, and cannot be used to evaluate any individual patient's condition. Applying it to assess these variables is a fundamental misuse of the tool that the researchers themselves do not sanction.

- **The LCRI distinguishes between those with and without a SARS-CoV-2 infection, not between LC and non-LC. It cannot be used as a Long COVID classifier and cannot be communicated as such.** The LCRI's LASSO model was optimized to distinguish between people who had and hadn't had COVID; the LCRI's symptom weights reflect how statistically unique each symptom is to SARS-CoV-2 infection relative to an uninfected comparison population, not how clinically significant that symptom is to Long COVID. Without ground-truth Long COVID labels, the model cannot learn what distinguishes LC from non-LC within the infected cohort. Calling the LCRI an LC classifier is an overstatement that the data structure fundamentally doesn't support.

- **The LCRI is not a measure of severity, symptom burden, or functional burden.** The symptoms identified in the LCRI are the most *unique* symptoms - not those with highest functional burden or impact to quality of life. The index assigns points based on population-level log odds ratios, not on clinical severity. Loss of smell or taste receives 7 points, while fatigue receives only 1 point, despite fatigue being the most commonly reported Long COVID symptom. Currently, a patient with debilitating fatigue, brain fog, and palpitations scores lower than a patient with anosmia alone. This is a research artifact, not a reflection of disease burden.

- **The LCRI is not validated for longitudinal measurement, and does not account for variant.** The proportion meeting the 2024 threshold was 33.8% among pre-Omicron participants versus only 12.7% during Omicron circulation. The index reflects epidemiological era and viral variant, not stable individual disease severity. Applying it longitudinally to the same patient across time conflates cohort-level shifts in symptom presentation with personal clinical change.

- **Symptoms included in the LCRI have vastly different resolution rates and natural histories, making aggregate scores uninterpretable over time.** Two of the three highest-weighted symptoms in the index — loss of smell/taste and chronic cough — are among the fastest to resolve. By contrast, the lowest-weighted symptoms – fatigue, brain fog – are among the most persistent.[7,8] The result is a systematic distortion: a patient's LCRI score will fall over time simply because their smell/taste or cough resolved, even if their fatigue, brain fog, and PEM are completely unchanged or worsening. The index would record this as improvement. A patient whose dominant symptoms are fatigue and brain fog will have a low and relatively stable score throughout their illness regardless of how their disease evolves, because the symptoms carrying the most points are those they are least likely to have. These differential resolution rates are not incidental but

[7] https://www.thelancet.com/journals/lanwpc/article/PIIS2666-6065(25)00044-6/fulltext
[8] https://pmc.ncbi.nlm.nih.gov/articles/PMC10978792/

structural to the index, and they mean that longitudinal changes in LCRI scores reflect the natural history of individual symptoms rather than any meaningful change in overall disease burden.

- **The LCRI fundamentally misshapes patient cohorts to include those more likely to recover and those with lower severity, deeply reducing the quality of Long COVID research and negating any findings.**
    - The top-weighted symptom on the index is loss of smell or taste – a symptom with multiple severe biases.
        - The presence of loss of smell/taste is associated with a less-severe patient phenotype and a higher quality of life, and negatively associated with debilitating and multisystemic symptoms such as fatigue and PEM; it is also one of very few symptoms that can occur on its own.[9,10,11] In RECOVER's own research, loss of smell/taste is a symptom disproportionately associated with low severity and high quality of life.[12]
        - Loss of smell/taste is associated with higher rates of recovery and resolution.[13,14]
        - Patients do not rank loss of smell and taste as a high burden symptom. In one study, loss of smell/taste ranked 27 of 27 most burdensome symptoms;[15] in another, only 2.8% and 1.1% of LC patients included loss of smell and taste in the most debilitating symptoms at 24 months, compared to 70% for fatigue.[16]
        - Prevalence of loss of smell/taste has dropped significantly in Omicron and later variants.[17,18]
        - Rates of smell/taste dysfunction are higher in populations with European descent.[19]
    - Chronic cough – the third-highest weighted symptom in the LCRI - is most common in RECOVER's second-lower severity group[20] and is also associated with higher rates of recovery and resolution.[21,22]

---

[9] Smell/taste associated with "few symptoms" phenotype and high quality of life https://www.sciencedirect.com/science/article/pii/S1876034125003430
[10] Smell/taste distinct phenotype, separate from multisystemic phenotype and fatigue/headache phenotype https://www.jclinepi.com/article/S0895-4356(25)00200-8/fulltext
[11] Smell/taste cluster associated with low frequency of fatigue, respiratory, and neurocognitive symptoms, and high quality of life and physical function. https://link.springer.com/article/10.1007/s00405-023-08163-x
[12] https://jamanetwork.com/journals/jama/fullarticle/2828329
[13] https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2024.1377866/full
[14] https://link.springer.com/article/10.1186/s12879-025-11468-3
[15] https://www.pnas.org/doi/10.1073/pnas.2426874122#supplementary-materials
[16] https://www.frontiersin.org/journals/epidemiology/articles/10.3389/fepid.2023.1144707/full#supplementaryMaterial
[17] https://aao-hnsfjournals.onlinelibrary.wiley.com/doi/10.1002/ohn.384
[18] https://www.sciencedirect.com/science/article/pii/S1201971226001578
[19] https://pmc.ncbi.nlm.nih.gov/articles/PMC9913864/
[20] https://jamanetwork.com/journals/jama/fullarticle/2828329
[21] https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2024.1377866/full
[22] https://link.springer.com/article/10.1186/s12879-025-11468-3

    - The result is that **the "likely LC" group with LCRI scores of ≥11 is systematically enriched for patients with better prognosis**, while the <11 group is likely enriched for patients with fatigue-dominant presentations who don't have loss of smell/taste or cough. **This inversion is a serious methodological problem that will affect every study using this design.** Papers that compare these cohorts to each other will create fundamentally uninterpretable and meaningless findings, resulting in not only resource waste but further obscuring the field of Long Covid research.

- **The LCRI's weighting enriches for certain subtypes and against others, which produces uninterpretable comparisons when a research question concerns an under-weighted symptom or condition.** Consider POTS, one of the most common COVID-onset conditions. A patient with POTS could present with brain fog (3 points), palpitations (2), fatigue (1), dizziness (2), and shortness of breath (2) – a classic dysautonomia presentation – and total only 10 points, falling below the LCRI threshold. Patients with this phenotype are then distributed across both the ≥11 and <11 groups depending on whether they happen to also have one or two additional symptoms, rather than being sorted by the severity or presence of their actual condition. **This becomes particularly problematic when a research question concerns one of these under-weighted symptoms or subtypes.** Because the LCRI does not weigh cardiovascular symptoms highly, patients with COVID-onset cardiac conditions will not sort cleanly into either the ≥11 or <11 group — they will be present in both. A study comparing, for example, EKG abnormalities between an LCRI ≥11 "Long COVID" group and an LCRI <11 "non-Long COVID" group is therefore not comparing patients with cardiac involvement to those without; it is comparing two groups that both contain cardiac patients, distributed according to whether they also happened to have one or two additional symptoms. The comparison cannot isolate the effect being studied, because the grouping variable is uncorrelated with — and in some cases inversely related to — the clinical feature of interest. Any finding from such a design is biased toward the null and fundamentally uninterpretable, and a null or attenuated result risks being misread as evidence that COVID-onset cardiac pathology is not part of Long COVID, when in fact it reflects only that the LCRI never sorted patients by that pathology in the first place.

- **LCRI misses a large swath of patients with new-onset conditions.** By only using symptoms, the LCRI misses all patients that have new-onset conditions from Long COVID - a crucial cohort in the more robust NASEM definition. New-onset conditions including cardiovascular and vascular disease, POTS and other forms of dysautonomia, diabetes and other metabolic and endocrine illnesses, autoimmunity, myalgic encephalomyelitis, kidney disease, and neurological impairment are all considered Long Covid.[23]

[23] https://nap.nationalacademies.org/resource/27768/One_pager_Long_COVID_Definition.pdf

Our Demands

As patient representatives, advocates, and researchers both within and external to RECOVER, we request that RECOVER cease using the LCRI, and replace the classification of Long Covid with a metric that better captures severity and the full patient cohort.

During this transition, we request that RECOVER urgently commit to the following requests incorporating the above information. We request that RECOVER provide dates that each action will be accomplished by, and provide email updates to all representatives on these actions. We request all actions be performed by October 15, 2026.

- **Issue a clear public statement** explicitly prohibiting the use of the LCRI for individual clinical assessment, severity determination, symptom or functional burden, improvement or worsening, recovery, or adjacent measures. This statement should be available on the RECOVER website and be emailed to all researchers. This should also be communicated directly to all authors proposing RECOVER publications that propose to mis-use the LCRI in any of these ways.

- **Stop requiring or suggesting the use of LCRI in RECOVER work**. Multiple researchers have stated that RECOVER is requesting they use LCRI in analysis; we ask that this stops immediately.

- **Create a new variable** that classifies whether the person does or does not have LC according to the NASEM definition, clinical judgment, and/or patient judgment; this should be used in any studies going forward.

- **Correct language when using LCRI:** For unpublished papers that have already used or plan to use LCRI in analysis, the LCRI should only be used to refer to the score itself. For instance, a paper using the LCRI cannot say “High symptom burden is associated with cognitive dysfunction”, but must say “LCRI scores are associated with cognitive dysfunction.”

- **Educate all RECOVER-associated researchers on the use and misuse of the LCRI, with confirmation of understanding.** It is the responsibility of RECOVER leadership to provide this education in a timely manner, and to create a system where researchers have acknowledged this to prevent further low-quality research from being released and to remove the burden of education from patient representatives.

- **Implement rules that ensure all RECOVER-associated research studies, papers, and proposals that misuse the LCRI will not be supported, approved, or published.** Precious RECOVER resources, including statistical support, should not be allocated to researchers who do not understand how to use the index. This system should be implemented at multiple checkpoints and in multiple committees before research begins,

and should be robust enough to catch all instances without the burden falling to patient representatives. The system should communicate that language and analysis are changed to be in line with the guidelines, and that any studies that performed analysis with the LCRI in an inappropriate manner must redo the analysis.

Respectfully and urgently submitted,

Teresa Akintonwa*
Dr. Alba Azola, Johns Hopkins School of Medicine*
Gina Assaf, Patient-Led Research Collaborative
Dr. Sanghoon Bae, Patient-Led Research Collaborative
Dr. Chloé de Canson, University of Groningen
Dr. Alison Cohen, University of California San Francisco*
Dr. Victoria Copeland, PhD, MSW, Empowerment Through Community*
JD Davids, JD Strategies
Dr. Todd Davenport, PT, DPT, PhD, MPH, FAPTA, University of the Pacific
Hannah Davis, Patient-Led Research Collaborative*
Dr. Deborah L. Durika, WWAMI School of Medical Education, Neuroversion Inc
Jon Douglas*
Liza Fisher*
Dr. Tessa Green, Patient-Led Research Collaborative
Yvonka Hall*
Billy Hanlon*
Norio Honjo, Patient-Led Research Collaborative
Nita Jain, Timeless Biosciences*
Prof. Abigail Koppes, Northeastern University
Julie S. Lam, MaskTogetherAmerica*
Philippe Lunardelli
Charlie McCone, Patient-Led Research Collaborative*
Dr. Mitchell Miglis, Stanford University*
Dr. Julia Moore Vogel, Scripps Research Institute
Kian Kim Ngyuen*
Dr. David Putrino, Icahn School of Medicine, Mount Sinai*
Dr. Signe Redfield, Patient-Led Research Collaborative
Samuel Rhodehamel
Catherine Romatowski, Patient-Led Research Collaborative
Jacqueline Rutter, Dysautonomia International*
Sandria L. Savage, BSN, RN*
Anisha Sekar*
Dr. Letícia Soares, Patient-Led Research Collaborative
Rivka Solomon*
Ezra Spier*
Doreen Stein-Seroussi*
Lauren Stiles, Dysautonomia International*
Toni Wall Jaudon, University of Arkansas
Jess Warner, BSN, RN*

*Denotes RECOVER researcher or patient representative