



August 19, 2024

To:

- Hilary Eirling, MPH, Partnership Team Lead with NCIRD & CDC
- Mandy Cohen, Director of CDC
- Demetre Daskalakis, Director of the National Center for Immunization and Respiratory Diseases (NCIRD)
- Kate Wolff, Chief of Staff
- Dr. Priti Patel, MD, MPH, Senior Advisor on Long COVID
- Leandris Liburd, Acting Director for CDC's Office of Health Equity (OHE)
- Nirav Shah, Principal Deputy Director
- Manisha Patel, Chief Medical Officer for the NCIRD, National Center for Immunization and Respiratory Diseases
- Shannon Griffin-Blake, Chief Disability Officer
- Brooke Barry, Associate Director for Policy for NCIRD
- Kathryn Weitzner, Public Health Analyst, NCIRD Office of the Director, CDC
- Kerry Caudwell, Senior Policy Analyst, Office of the Chief of Staff, CDC
- Natasha Buchanan Lunsford, Health Scientist, Office of the Director, NCIRD, CDC

We hope this letter finds you well. We are writing on behalf of Long COVID Justice to follow up on our August 9 meeting, and to discuss several pressing concerns related to Long COVID and the CDC's current policies.

In alliance with our partners at Pan End It, Mask Together America and other groups, we support these three vital requests to confront and overcome the ongoing COVID/Long COVID crisis:

- CDC must issue a better isolation guidance aiming to reducing transmission - ideally 10 days in length - that is specific to COVID-19, includes masking and testing as core prevention strategies, and with improved messaging on the importance of COVID-19 prevention and basic information about COVID-19 and Long COVID
- CDC must provide more specific and detailed guidance for groups and individuals who are high-risk on protecting themselves, including disabled individuals and incarcerated people
- CDC must directly and meaningfully including disabled people who are most impacted by COVID-19 - including people with Long COVID and high-risk people of all ages - into CDC decision-making processes, such as the development of isolation and masking policies and messaging materials

Firstly, we greatly appreciated the opportunity for a productive discussion. We recognize that everyone who was there – whether CDC staff or from the COVID/Long COVID advocacy community – is committed to doing all we can to address these issues. Towards that end, we invite you all to reach out at any point to share information, experiences or perspectives.

We appreciate your agreement to have a Long COVID-focused meeting with Long COVID Justice and partner groups. This would allow us to explore in greater depth the current and potential chronic impacts of COVID-19 policies, and how these policies could be adapted to better address Long COVID. *We look forward to working with Dr. Patel and others to coordinate this meeting to ensure representation from key partners and constituents who we believe have not had adequate opportunity to speak with CDC on these issues*

As an organization, we often look to the successful federal effort on HIV/AIDS as a model for addressing Long COVID and the ongoing COVID-19 crisis. We recognize that achieving substantial progress in this area requires significant funding and resources, which we hope the CDC will advocate for to the extent permitted by its role in the federal government.

One immediate action we believe is overdue involves enhancing the CDC's community consultation practices. **We urge the CDC to adopt and adapt the strong practices of community engagement used in your HIV/AIDS bureau.** This includes consulting and listening to disabled and chronically ill individuals, particularly those from the most affected communities such as BIPOC and transgender individuals.

We appreciate your request to give input into public communication materials for what you refer to as the upcoming respiratory virus season. **Please contact us as soon as possible so we can assist.**

In addition, we want to highlight **the need to consistently describe COVID-19 as a condition with both acute and chronic facets.** Long COVID is persistent and prevalent, and it is critical that this be reflected in all communications about COVID-19. Mention of COVID-19 should always include chronic aspects, unless the mention is truly *only* about the acute phase of COVID-19.

This should be implemented not only in terms of editorial practices for public-facing content and provider education, but also in terms of the data used to evaluate the effectiveness of COVID-19 mitigation policies. Hospitalization and deaths from acute COVID offer a very limited picture of COVID-19's impact, with 400 million people worldwide suffering from Long COVID.

We are deeply concerned that the CDC and other federal agencies have contributed to **the misconception that COVID-19 is solely an acute illness.** We know this is not solely a challenge with federal partners but a widespread issue. As we mentioned in the meeting, we conducted an analysis of Washington Post reporting on COVID from March to June 2023, revealing that only 10-15% of opinion and news coverage on COVID even mentioned Long COVID.

In addition, we will be providing full feedback on the suite of **COVID and Long COVID pages on the CDC website which continue to have misleading, incomplete or inaccurate information.** For example,

on the page titled Signs and Symptoms of Long COVID, the second “key point” at the top of the page reads:

- Most people with Long COVID symptoms see significant improvement after 3 months, while others may see improvement up to 6 months after symptoms first appear.

People with symptoms of less than 3 months duration do not have Long COVID. It is very common for full resolution of symptoms from acute COVID to take weeks to months, and misleading to imply that those who experience symptom resolution in this time had had Long COVID – a condition for which full recovery is rare (Tran, V.-T., Porcher, R., Pane, I. & Ravaud, P. Course of post COVID-19 disease symptoms over time in the ComPaRe long COVID prospective e-cohort. Nat. Commun. 13, 1812 (2022).)

Moreover, we find the current CDC guidance on COVID-19 to be deeply problematic from a health equity perspective. **The current isolation guidance assumed that it is feasible to identify “high-risk” individuals and adjust practices accordingly, which is literally impossible and exacerbates the ongoing crisis.** In addition to exacerbating COVID harms, the guidance may also contribute to misunderstanding and stigma surrounding chronic illness, disability, and immune-compromised individuals.

We request **clarification on what data was used in order to create the guidance, any communications research used to understand public interpretation, and details on which metrics will be used to evaluate its impact and possible collateral harms.**

We also request **a full list of which external partners from disability and chronic illness communities were consulted** in the formulation of the guidance and other COVID-19 related policies and activities in 2023 and 2024.

Additionally, **CDC’s definition of “high-risk” should encompass those at elevated risk for Long COVID, not just those at higher risk of acute COVID-19 harms.** This includes marginalized groups such as transgender individuals and those living with HIV, regardless of viral load.

The lack of emphasis on Long COVID and integration of Long COVID across all content on COVID-19 is harmful not only for those of us with Long COVID facing stigma and barriers to care, treatment and support. Broader harms include:

- **Contributing to a climate of misinformation and disinformation.** For example, anti-vaccine interests have seized upon widespread morbidity and mortality from Long COVID to claim it is caused by vaccination, perpetuating a cycle that undermines vaccination efforts and increases Long COVID cases.
- As millions of people go on to develop Long COVID under this guidance, including in non-seasonal waves, we fear **further diminishment of trust in public health measures and medicine**, which could have far-reaching consequences for future pandemics.

Fundamentally, we are concerned about **the apparent absence of evaluation or analysis of CDC communications and guidance regarding COVID-19 and Long COVID.** We seek clarity on the goals of

current guidance, the metrics for evaluating success, and how the CDC plans to address the impacts of less-mitigated COVID-19 waves.

Lastly, we urge the CDC to **address the vacuum of federal leadership that has allowed misinformation and disinformation to flourish.**

The recent violence related to mask bans and mixed messaging from various officials underscores the urgent need for clear, consistent guidance. **We strongly recommend that the CDC expedite an advisory or brief on the collateral harms of mask bans.** We recognize it can't explicitly reference pending legislation, but urge you to consider the **CDC's important efforts on HIV criminalization as a model** for your role in educating local, state and federal entities on public health aspects of criminalization policies.

Thanks again for your time and commitment. We know that Long COVID has touched each of our lives, families and/or communities. We welcome you to come to us as partners and allies, whether in your roles at CDC or outside of those roles.

We look forward to your response and hope to schedule a follow-up meeting to discuss these critical issues further. Thank you for your attention to these matters.

Sincerely,

JD Davids

Co-Director, on behalf of Strategies for High Impact / Long COVID Justice