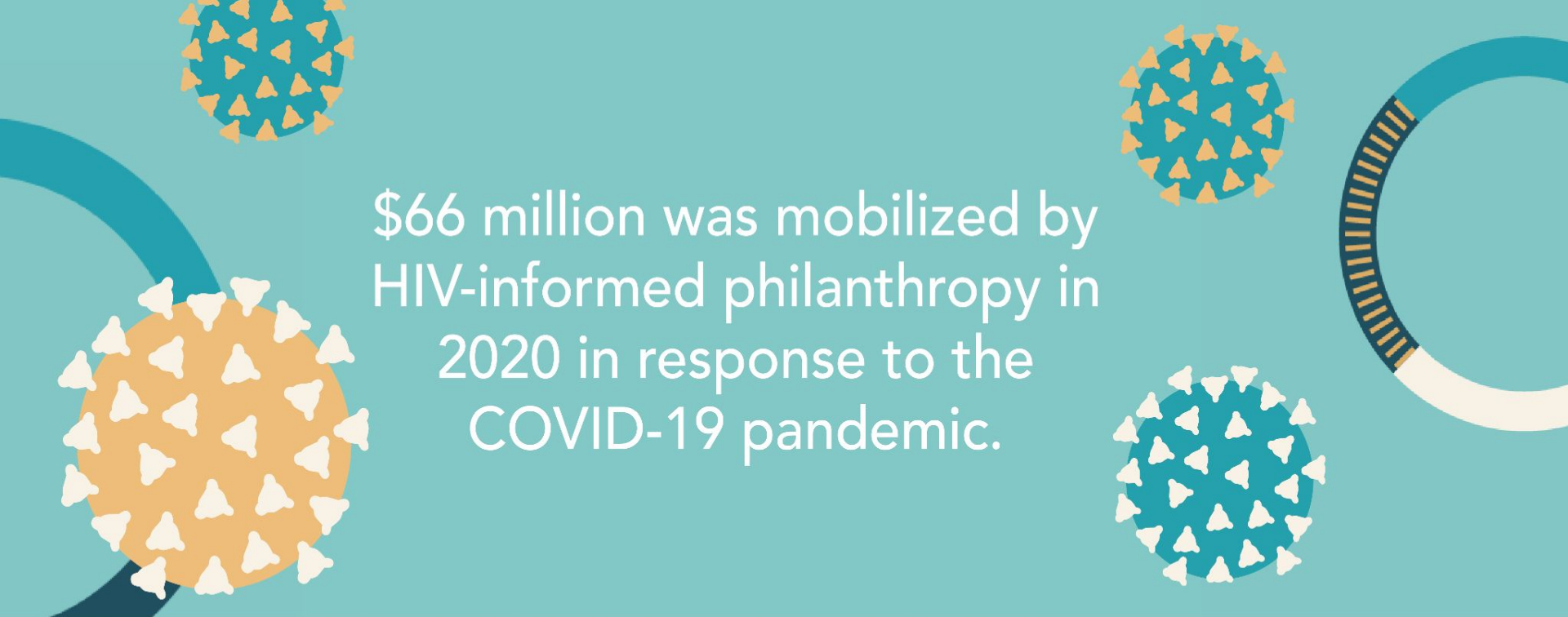


PANDEMICS ARE CHRONIC: A CONVERSATION WITH HIV AND DISABILITY FUNDERS ON COVID & LONG COVID.

Thursday, 8 December 2022





\$66 million was mobilized by
HIV-informed philanthropy in
2020 in response to the
COVID-19 pandemic.



Philanthropic Support to Address HIV and AIDS in 2020



THANK YOU TO OUR CO-SPONSORS

FUNDERS FOR

JUSTICE

<https://fundersforjustice.org/>

25 YEARS OF
youth vision and activism for gender justice

THIRD WAVE FUND

<https://www.thirdwavefund.org/>

ATTENDEE LOGISTICS

- **Translation**

- Available in Spanish, ASL and closed captions (see red arrows)

- **General**

- All attendees will be on mute
- This session will be recorded
- You can offer comments via the chat or questions via the Q&A function, or via the reaction tools (see red arrows)
- This is a non-solicitation space.



Q&A

Polls

Chat

Share Screen

Record

Show Captions

Interpretation

Reactions

Apps

Whiteboards

More

Pandemics Are Chronic

Founded in January, S4HI is a non-profit hub for collaboration, communication and action.

S4HI is powered by disabled and chronically-ill people and dedicated to creating durable, inclusive solutions in public health, policies and systems.



StrategiesForHighImpact.org

Connections and disconnections between movements and practices: HIV/AIDS and Disability



Photo credits for fair use: left: film still, Crip Camp; right: Creator: STUART RAMSON, AP

What is Long COVID?

Official definitions vary but generally include:

- **Affects 1 in 5 people** -- children, adults and elders -- who have had SARS CoV-2 - whether or not they have had a confirmatory test.
- **Symptoms can continue from an acute COVID infection, emerge 1-3 months after initial infection, or fluctuate.** They last for at least two months and cannot be explained by any other diagnosis.
- **Symptoms documented to date can affect all organ systems** – the most common symptom is debilitating fatigue. About half of people with Long COVID may have ME/CFS (myalgic encephalomyelitis).

What is Long COVID: Not Surprising or Rare, But Huge

One year ago, WHO estimated that over 100 million people worldwide already had Long COVID

In the US:

- **7.1 percent of all US adults** report currently experiencing Long COVID symptoms
- **5.8 percent** report that their Long COVID symptoms limit their activities
- **Nearly 2 percent** report that their daily activities are limited by a lot

One million Americans are out of work at any given time due to Long COVID.

The economic cost -- lost income, loss of health, additional medical care - \$3.7 trillion USD**

David M. Cutler, *The Cost of Long COVID: An Update*, Harvard University,
https://scholar.harvard.edu/files/cutler/files/long_covid_update_7-22.pdf

National Center for Health Statistics: Long COVID Household Pulse Survey:
<https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

A mass disabling event with costs that rival, in aggregate, the Great Depression.

What is Long Covid?

According to people with Long COVID...

- **A huge disruptive force** in every areas=a of how they are living their lives. For already chronically ill and disabled people, it can be a worsening of existing states or entirely new challenges added on.
- **A condition that MUST be defined broadly** – Long COVID and Associated Diseases – to acknowledge conditions such as dysautonomia and ME/CFS, which are present in people with Long COVID and related complex chronic conditions that often occur as sequelae from viruses
- ***A condition that requires centering care and caregivers***

What is Long COVID?

Through the strategic lens of Strategies for High Impact (S4HI)...



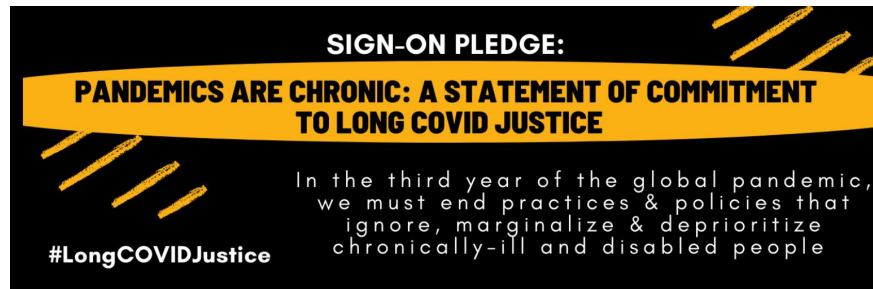
Another chronic pandemic colliding with, exacerbating and activating forms of care, organizing and patient-led research developed as responses to marginalization and neglect of people living with HIV, people with disabilities, queer, BIPOC and chronically ill people by the US and global health systems.

A massive challenge and a huge opportunity.

Pandemics are Chronic | tinyurl.com/PandemicsAreChronic

In the third year of the pandemic, we must end practices and policies that ignore, and further marginalize, disabled and chronically-ill people. We ask you to join us in a pledge:

- **To include** Long COVID in the narrative of the COVID-19 pandemic; we cannot tell the story of COVID without discussing Long COVID.
- **To center, platform, and resource** those with Long COVID, complex chronic illnesses, and other disabilities at the forefront of policy, advocacy, and action related to these issues.
- **To work** to end the marginalization of disabled and chronically-ill people, which is a constant and widespread harm, existing outside of and across all aspects of pandemics.
- **To recognize** that the COVID-19 pandemic and Long COVID have disproportionately impacted already marginalized communities, including Black, Brown, and Indigenous communities.



Resourcing the HIV Community to Face COVID-19 and Long COVID

HIV, COVID-19, and Long COVID: Pandemics Intertwined

Michael Peluso, MD

Assistant Professor of Medicine
Division of HIV, Infectious Diseases, and Global Medicine
University of California, San Francisco

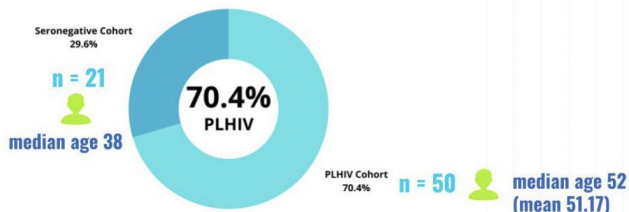
michael.peluso@ucsf.edu



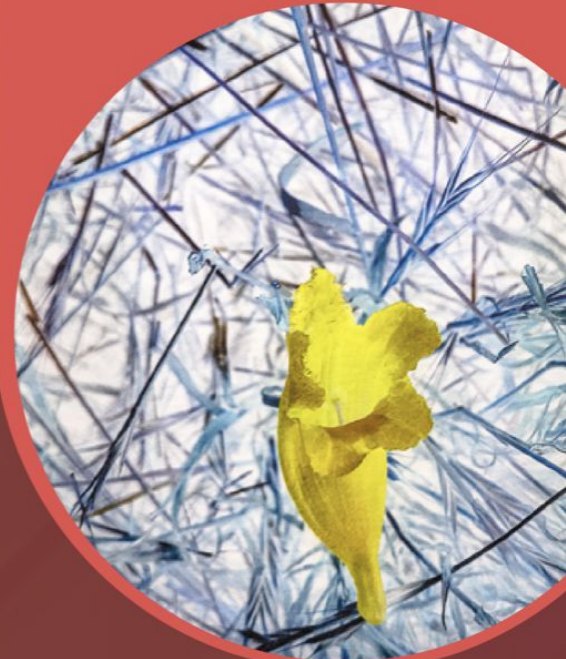
I have no conflicts. There are very limited high-quality data and standards of treatment for Long COVID, so much of what I will discuss is based on experience or expert opinion.



Sample n = 71  Age Range 25-77 y/o and median age 51 (mean 48.75)



bit.ly/HIVreport



Network for
Long COVID
Justice

Strategies for
High Impact

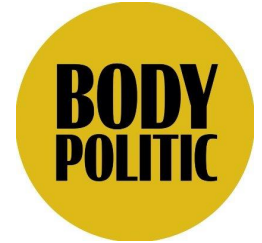
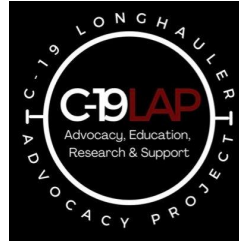
Springboard
Health Lab

Resourcing the HIV Community to Face COVID & Long COVID in 2022

**Project Report:
Findings, Recommendations, and Resources**

May 2022

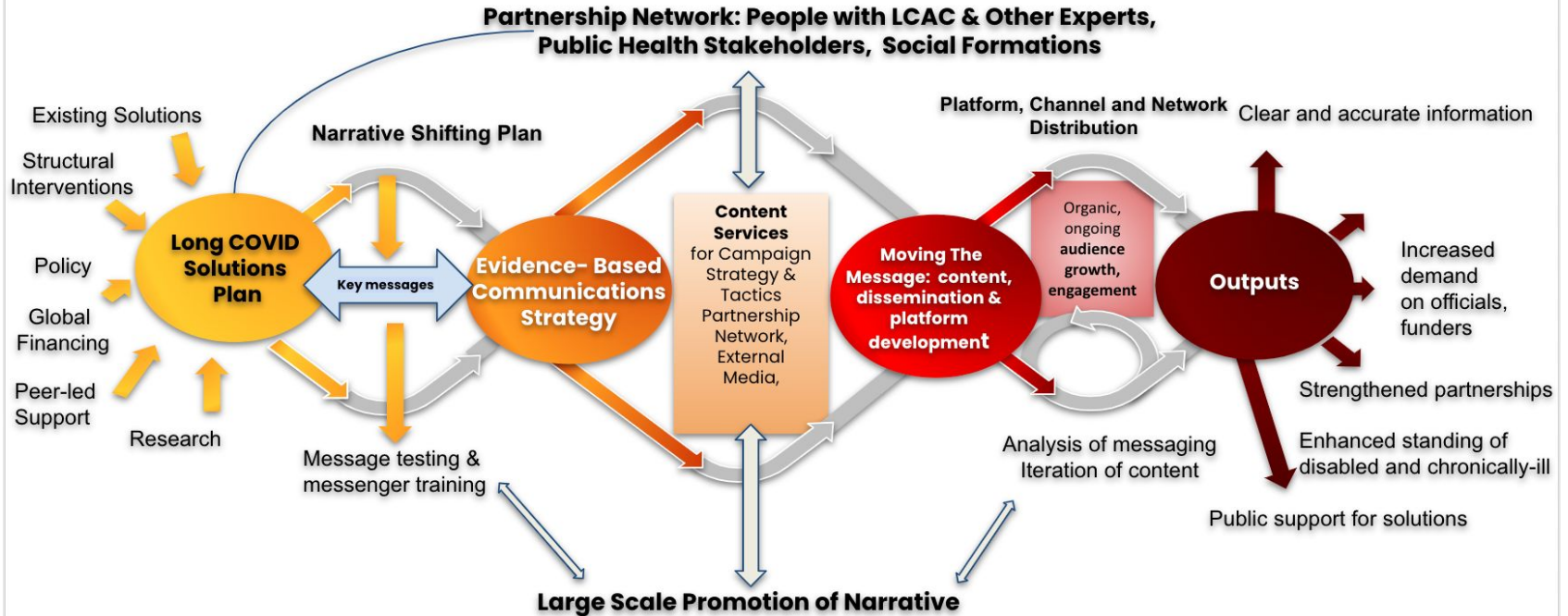
The Network for Long COVID Justice



**PATIENT-LED
RESEARCH
COLLABORATIVE**



The Long COVID Communications Resource Project



The crucial role for philanthropy and community



Racial Justice in HIV Philanthropy Guiding Principles

November 2021



**Disability &
Philanthropy
Forum**

Discussion questions

How can funders and advocates working to build a healthy, sustained response to long COVID, disability, chronic illness and colliding pandemics learn from HIV and disability movements when it comes to principles and practices?

What does an integrated, well-resourced and justice-oriented advocacy movement for addressing chronic pandemics look like?