TOO MANY DEATHS, TOO MANY LEFT BEHIND:

A PEOPLE'S EXTERNAL REVIEW OF THE CDC

People's CDC

EXECUTIVE SUMMARY

The US population has suffered worse health consequences due to COVID-19 than comparable wealthy nations. COVID has caused over 1.1 million deaths in the United States and contributed to a 3-year decline in life expectancy. When the CDC announced an external review to investigate this evident failure, the People's CDC, a coalition of public health workers and community activists, launched a People's External Review. We surveyed nearly 500 public health experts and community leaders and reviewed over 200 journal articles, government reports, news articles and white papers. Ultimately, we found that the CDC has failed to adequately inform the public that COVID remains a serious threat, in contradiction of its own science. The CDC has increasingly recommended policies which put individual choice over population health. As a result, large swaths of the population, including older adults, disabled, chronically-ill and immunocompromised people, can't meet their basic needs without risking COVID-19. The public deserves accurate information and guidance from their government, based on the latest science, and that is the CDC's job. Everyone deserves their best chance to be healthy. The CDC should put public health first and partner with communities most impacted by the pandemic, share evidence-based information, and encourage people to protect each other using layered protections to decrease COVID-19 transmission. As emerging variants can already evade existing vaccines and treatments, and the end of the state of emergency threatens to leave millions without health insurance, access to COVID vaccines, tests and treatments, a multifaceted, sustainable approach to the COVID pandemic is essential to protect people, the economy, and future generations.

Introduction

In 2020, the first 100,000 deaths from COVID-19 shocked the nation. However, when U.S. COVID deaths surpassed the 1.1 million mark in January 2023,[1] rather than pausing to acknowledge the grave loss, President Biden moved to end the COVID-19 State of Emergency. In 2022 alone, a year when many politicians and even some medical professionals had suggested the pandemic was over, more than 250,000 people in the United States died from COVID.[1] COVID remains the third leading cause of death in the United States since the pandemic began.[2,3] More than 1,600 children have died from COVID-19,[4] making COVID one of the top 10 causes of childhood death since the beginning of the pandemic.[5] More than 200,000 children have lost a caregiver since the

beginning of the pandemic.[6] Meanwhile, as many as 36 million people in the United States have experienced Long COVID,[7,8] which is keeping nearly 4 million people out of work in the United States alone.[9]

Amid this terrible pandemic, some public health professionals and community activists observed that the CDC was straying from its noble history of promoting evidence-based public health. We identified three major "red flags:"

1. **The CDC leadership downplays the serious threat COVID-19 continues to pose,** likening COVID to the flu[10] and creating maps that deemphasize the risk of COVID transmission instead of aiming to control and prevent disease.

2. **The CDC leadership has shifted recommendations following pressure from influential business interests[11] and has aligned public health guidance with political agendas[12] over scientific evidence** to create an atmosphere where workers and consumers are willing to put their lives and health at risk to work and shop in unsafe conditions.

3. **CDC guidance pushes individual choice over a population health approach to protect everyone.[13] This approach devalues the lives of high-risk individuals** (4 in 10 US adults[14]) **by burdening them to protect themselves,**[15] instead of encouraging everyone to protect each other.

In January 2022, we formed the People's CDC, a volunteer-run coalition of public health practitioners, scientists, health care providers, educators, advocates, and people from all across the country passionate about reducing the harmful impacts of COVID-19. The CDC and elected leaders often reference the need to "meet people where they are,"[16] when removing public health protections, but repeated polls show the U.S. public favors COVID-19 protections, such as mask requirements, when infection rates are high.[17–19] Because of misleading messaging from the CDC, most people do not know when COVID-19 transmission rates are high.[20] Those who do are more likely to protect themselves by wearing masks.[20] As the People's CDC, we also believe a well-informed public would agree we should not tolerate hundreds of thousands of deaths each year from COVID-19. When we learned the CDC was carrying out an internal review of its work, we decided to carry out a "People's Review of the CDC." We surveyed nearly 500 health workers, community leaders, and public health researchers and practitioners. We asked them to evaluate the CDC's performance in eight key areas of pandemic management. Our findings underscore the concerns that brought us to this investigation.

Key Findings

We assessed and made recommendations for improvement of the CDC's pandemic management in eight key areas: disease control and prevention, ethics, equity and justice, scientific integrity, public health infrastructure, communication, inclusion, and addressing root causes.

1. Disease Control and Prevention: Collect and use high-quality data to promote a multifaceted approach to prevent and control disease transmission.

"The CDC should be consistently noting the airborne nature of COVID-19 as top-line messaging, and guiding local and state health departments to likewise do this, with appropriate airborne mitigation that goes beyond masking to include air ventilation, air filtration, and UVGI. . . .We have many tools for reducing airborne mitigation risk that the CDC and other Federal agencies are not emphasizing appropriately"

–Anonymous Public Health Policy Researcher, Illinois

Red flags:

- The CDC emphasizes vaccines and medical treatments rather than acknowledging the public health threat the COVID pandemic continues to pose and advocating for a comprehensive strategy to prevent COVID transmission.[13] This strategy encourages unmitigated spread of COVID-19 and promotes the emergence of new and potentially worse variants, such as XBB and BQ subvariants,[21] which can already evade existing vaccines and COVID treatments and may ultimately prolong the pandemic.

- The CDC changed the maps that trigger COVID mitigation measures to emphasize hospitalization rates instead of case numbers. The risk of being exposed to COVID-19 is related to case rates rather than hospitalizations. The new map also builds a delay into the public health response by basing public health guidance on a lagging indicator (hospitalizations) and essentially eliminating a leading indicator of virus spread (case numbers).[22]

- Allowing COVID-19 to spread increases everyone's risk of catching COVID multiple

times. Repeated COVID infections increase the risk of Long COVID,[23] which can even affect children.[24]

Recommendations for Control and Prevention of Disease:

- **The CDC should promote a comprehensive, layered public health strategy to reduce COVID transmission,** including the combined use of masks, ventilation, testing, and vaccines, among others, to filter the virus out of the air and decrease COVID transmission.[25]

- **The CDC should better educate the public that the SARS-CoV-2 virus, which causes COVID, is airborne,** meaning transmission happens through aerosols that can accumulate in the air when infected people exhale, talk, sneeze, or cough, especially in enclosed, poorly ventilated, indoor settings.[26,27]

- **The CDC should implement early warning systems to prevent surges** by using local community transmission (corrected for low rates of testing) and wastewater data to trigger mitigation measures, instead of the Community Levels map, which emphasizes hospital capacity rather than sickness and Long COVID.

- **The CDC should recommend data-driven mask mandates, which are highly effective at reducing the risk of COVID transmission[28–31] and which most of the U.S. public supports to prevent surges** when transmission rates are increasing.[17,18,32] In particular, the CDC should recommend the Transportation and Security Administration (TSA) mandate masks on public transport,33 which most Americans support.[19] The CDC should also recommend universal masking at all times in health care settings, where vulnerable people face a high risk of being exposed to COVID-positive people (with or without symptoms) seeking care.[34,35]

2. Ethics: Emphasize the equal value of all people's lives in policy decisions.

"I am a high-risk person with chronic illness who has feared for my life for most of the last 3 years. Now, CDC policies have completely left disabled people behind as if our lives are disposable because abled people don't want to wear masks. Abled people's convenience is not worth more than disabled people's lives."

– Christine Mitchell, ScD, MDiv, Public Health Justice Collective, California

Red Flags:

- The CDC's approach **devalues the lives of communities disproportionately impacted by COVID and burdens them to protect themselves.** Universal masking is much more effective than individual masking to prevent COVID transmission,[36,37] and some people cannot wear masks. **If we do not require masks during surges, then we effectively require people to be subject to greater risks of being exposed to COVID, which undermines their autonomy.**

- In March 2022, CDC Director Walensky stated, "We will have a coronavirus that will lead to death in some people every season that we will then tolerate in some way."[38] **The decision to tolerate preventable deaths in disproportionately vulnerable groups, in exchange for the convenience of more able-bodied, younger, wealthy, and white individuals, is unethical and demonstrates a reckless disregard for the lives of communities disproportionately impacted by COVID.**

- The CDC has reported on the efficacy of masks and mask mandates in preventing COVID transmission.[29,39,28] Despite these data, the CDC only recommends masking as an individual choice rather than advising local and state public health institutions to require universal masking when COVID transmission rates are high.[40] **Because the CDC no longer recommends mask mandates explicitly, many institutions cite CDC guidelines as the principal reason not to mandate masks.**[41,42]

- **The CDC encourages the U.S. population to incur short- and long-term risks of COVID infection without their informed consent,** understating the risk of "medically significant illness" from COVID,[13] which continues to be the third leading cause of death in the United States since the beginning of the pandemic.[3]

Recommendations for an Ethical Pandemic Response:

- The CDC should promote community care and foster *interdependence*[43,44] over individualism, for the benefit of all rather than the most resourced, and encourage those in power and the public to participate in our collective responsibility to protect each other and public health.

- The CDC should inform the public of the true risk of COVID infection and illness to enable informed consent regarding COVID exposure and provide transparent, evidence-based policy recommendations, which emphasize the value of all people's lives, especially those at highest risk of severe illness from COVID-19.

- The CDC should protect people's autonomy by recommending policies which allow people to meet their basic needs and participate in society without being exposed to COVID-19. Such policies include increasing access to layered protections, such

as improved ventilation, free PCR and rapid tests, and requiring masks in public spaces and essential settings including classrooms, workspaces, public transit, and healthcare settings, as well as accessible in-person and robust online options for work and school.

3. Equity and Justice: Prioritize protecting the health of disproportionately impacted or vulnerable people and communities.*

"The pandemic response has failed to promote policies that prioritize the most vulnerable groups and communities and has left the primary responsibility for staying safe up to each individual. We urgently need a collective, equity-centered response..."

- Oni Blackstock, MD, MHS, Health Justice, New York

Red Flags

- Death and illness from COVID have disproportionately impacted structurally marginalized and minoritized populations, including immunocompromised, chronically-ill and disabled people; in-person workers, including health care workers; people who live in congregate facilities or who are incarcerated; older adults; and low-income communities, immigrants, and Black, Indigenous, and People of Color (BIPOC).[45–55]

- Marginalized groups face increased risk of COVID-19 infection, disability from Long COVID, and death because they are more likely to have been exposed to COVID in workplaces, schools, or crowded living spaces among others.[56,57] We chose the words "marginalized and minoritized" rather than "minorities" to name that these groups have been disadvantaged not because of genetic or cultural differences but rather because they have experienced historic and ongoing racial, gender, sexual, and/or class discrimination by the political, economic, legal, educational, and medical institutions of the United States.[58]

- The Biden administration announced a plan to end the COVID-19 Public Health Emergency, at a moment when COVID continued to cause over 450 deaths in the US daily,[1] without addressing the inequities which made the United States more vulnerable to the COVID-19 pandemic than other wealthy nations in the first place.

Recommendations for a More Equitable and Just Pandemic Response:

- **The CDC should partner with impacted communities to increase access to COVID public health protections,** including improved ventilation, tests and treatment, workplace protections, adequate paid leave, and health care. The CDC should advocate for increased funding for Long COVID research and access to experimental treatments and advocate for global vaccine equity.

- **The CDC should publicly advocate for the COVID-19 Public Health Emergency measures, which expanded access to health insurance, paid leave, SNAP benefits, improved ventilation, and COVID vaccines, testing and treatment, among others, to be made permanent and expanded upon** in order to address inequities and build a resilient public health infrastructure for this and future pandemics.

4. Scientific Integrity: Provide evidence-based guidance to protect public health over business and political interests.

"The CDC is the organization that many have looked to for clear, consistent, evidence-based guidance. At my university, our multi-hazard response plan for pandemic (pre-2020) always said to defer to the guidance and communication from the CDC. . . .But this time, the communication was inconsistent and often seemed more politically driven than evidence-based. . . .The biggest issue I noticed was the politicization of public health. The CDC should be nonpartisan and should safeguard the health of our nation, uniting us, rather than tearing us apart."
–Marissa Brash, DrPH, EdD, MPH, CPH, Department Chair and Associate Professor, Azusa Pacific University, California

Red Flags:

- The CDC's MMWR reports provide evidence of the risks of COVID-19 and the efficacy of combined mitigation measures, like masks, testing, ventilation, and isolating when sick to limit the spread of COVID-19; however, CDC leadership has shifted policy guidance away from its own scientific evidence in response to pressure from business[11] and political[12] interests.

Following industry pressure, including a letter from Delta Airlines CEO to CDC Director Walensky,[11] the CDC shortened the COVID isolation period from 10 days to 5 days, without a firm basis in evidence.[59,60] In spite of later evidence, including a CDC report, which showed that many people infected with Omicron remain contagious for at least 10 days,[61–64] the CDC did not update the 5-day recommendation, instead further entrenching it by recommending COVID-positive school children isolate for only 5 days.[13]

The People's CDC notes the double standard exposed during federal officials' bouts with COVID.[65] **Everyone should have access to such protections.**

- Before an in-person June 2022 interview with Dr. Anthony Fauci, chief medical advisor to the President, a **Washington Post** reporter tested positive for COVID and was required to "test negative three days in a row and wear a mask, even outdoors"[66] during the interview.
- President Biden took measures "above and beyond" CDC guidelines when he had COVID in July 2022, choosing to isolate until he tested negative.[67]
- CDC Director Walensky worked remotely during a rebound COVID infection.

Recommendations to Safeguard Scientific Integrity:

The CDC should base public health guidance on scientific evidence and minimize potential corporate and political conflicts of interest in policy development and implementation. CDC guidance should be based on its high-quality MMWR data and reporting instead of on politicians' opinions about what the public will tolerate. Given appropriate information, people can make their own decisions.

5. Public Health Infrastructure: Build capacity to prevent, control, and eliminate pandemics by supporting and collaborating with public health and medical institutions, community organizations, and other practitioners.

"Note that my recommendations are both to the CDC and to the executive branch and Congress to which CDC answers and on which it is dependent. The diversion of funding from non-COVID activities, both within the CDC and state and local health departments made clear that public health is way underfunded. . . . That COVID surveillance was . . .at the discretion of local/state

DOHs was an enormous problem . . .pathogens do not respect state borders and . . .infection reporting should be both standard across states and be driven by science and not the politics of hiding (underreporting) cases."

– David Perlman, MD, Infectious Disease Professor

Red Flags:

We acknowledge much of the U.S. public health infrastructure exists beyond the scope of the CDC's power; however, the CDC has failed to provide consistent and centralized leadership, leaving state and local public health agencies to interpret and enforce public health regulations.[68,69] The United States has also failed to invest adequately in community-based public health resources, like community health workers, public health nurses, and others.

Lack of data inhibits pandemic control efforts.

- Only 4% to 5% of COVID infections are reported,[70] which makes wastewater data essential to monitor spread of the virus; however, wastewater data are not developed adequately across the United States. Inadequate funding for genetic sequencing has impeded efforts to track spread of existing variants and identify new variants of concern.[71]
- Fragmented data collection complicates access to data, including race, ethnicity, occupational, disability, sexual orientation, and gender identity data, which inhibits our ability to identify and address the needs of the most impacted groups.[72,73]

Recommendations for Pandemic Public Health Infrastructure:

The CDC should facilitate improved coordination of the U.S. public health infrastructure and advocate for more equitable resource distribution.

The CDC should streamline and improve national data collection, including further developing wastewater data and viral sequencing.

The CDC should develop a robust, grassroots public health workforce in partnership with community organizations in impacted communities.

The CDC should advocate for increased funding and requirements for ventilation, air filtration[74–76] and explore the potential for UV technologies[77] to improve indoor-air quality in public spaces.

6. Communication: Build trust through evidence-based, accurate, effective, and accessible communication.

I admin a COVID-19 advocacy Facebook group in SC that has ~30K members. We spent immense volunteer time translating ever-evolving pandemic policies released from the CDC for lay audiences. The public health communication efforts were a consistent sore spot. In addition, some of the statements did not reflect the current research . . . I have a child with special needs, am personally immunocompromised, and have a husband with heart failure. So much of what was communicated by the CDC seemed ableist."

– Anonymous Public Health Researcher, South Carolina

Red Flags

- The CDC downplayed the risk of becoming infected with COVID-19 by changing the map it uses to trigger COVID mitigation measures to focus more on the rate of hospitalizations than the rate of COVID transmission.[78] In effect, the new Community Levels map made the U.S. COVID risk level switch from high risk to low risk (and the map from red to green) with the same data on the same day.[79] A recent CDC survey showed most people did not know when spread was high in their community.[20] Those who did were more likely to wear masks to protect themselves.
- The need to "meet people where they are"[16] should not be confused with basing COVID-19 guidelines on scientific evidence.

Recommendations for Pandemic Communications Strategy:

- The CDC should educate health care workers and the public about the serious risks COVID and Long COVID pose to all, including young, healthy, and vaccinated individuals.
- The CDC should communicate local COVID risk to the public using community transmission rates and wastewater data instead of the Community Levels map
- The CDC should "meet people where they are"[16] by developing evidence-based, effective, and accessible communications strategies in partnership with affected communities.

The CDC should recognize communication strategies are limited by the structural contexts people face. Combine communications with a structural strategy to implement institutional COVID protections in schools, workplaces and other public spaces.

7. Inclusion: Design and implement public health policy in partnership with all impacted communities*

"The Centers for Disease Control and Prevention's (CDC) ongoing failures have not gone unnoticed, in particular by the groundswell of people irrevocably harmed. Many pandemic victims have spent the last several years bringing attention to the need for a national pandemic overhaul to spare others from their pain, only to be ignored or dismissed by decision-makers, including CDC Director Rochelle Walensky."

– Kristin Urquiza, MPA, lost her dad to Covid in June 2020 & co-founded Marked By Covid, the grassroots network of Covid-bereaved individuals leading the national movement for pandemic justice and remembrance.

Red Flags

CDC guidance for immunocompromised people, older adults, and others at risk for serious illness from COVID focuses on precautions for individuals,[13] which are inadequate when not implemented universally at an institutional and community level. The CDC estimates about 4 in 10 adults (92.6 million people) are at higher risk of developing serious illness if they become infected with COVID due to older age or health condition.[14] Individual COVID action plans, as the CDC recommends, are inadequate to prevent COVID-19 infection in crowded indoor spaces. Many people at high risk of severe illness from COVID cannot fulfill their basic needs without risking COVID infection, because they or members of their household must go to work, school, or medical appointments or other settings, which lack COVID mitigation measures.

Recommendations for an Inclusive Pandemic Management Strategy:

The CDC should develop health policy and communications in partnership with groups that are disproportionately impacted by COVID and create federal, state, and local COVID-19 advisory committees with authority to shape health policy.

Inclusive policies should use layered prevention measures at the institutional level, rather than burdening individuals to protect themselves.

- Public health agencies at local, state, and federal levels should **integrate occupational safety and health advisory boards**, with representation from labor unions and workers' centers, to co-develop workplace safety guidance and enforcement strategies.

- **The CDC should express support for** a federally-recognized Covid Memorial Day and permanent national Covid memorial to honor the over 1,120,000 people who have lost their lives to COVID-19 as of this writing, and to honor the wishes of COVID-bereaved families. Formal recognition of these tremendous losses should draw attention to the importance of redressing social inequities and building robust and equitable public health systems to avoid repeating such a tragedy in the future.

8. Addressing Root Causes: Advocate for public health policy to address social, structural, economic, environmental injustices to promote health equity

"As a family medicine physician I worked closely with community-based organizations and community members working to serve their disproportionately impacted communities as the systems (health, public health, government) continuously left them behind. I experienced leadership at ALL levels…continuously make decisions that reinforced and maintained the pandemic disparities of our most-impacted communities...The answer is listening to the perspective and expertise of community, bring them to the table, and actually make them decision-makers. The most effective programs and outreach came from working with and following the lead of community."

- Jenny Fish, MD, on behalf of Health Professionals for Equality and Community Empowerment (HPEACE), California

Red flags:

- Even equipped with the best health information, many people are unable to follow public health recommendations due to structural factors in their living and working conditions, such as access to health care; safe, affordable housing; and paid sick

leave. However, the CDC has increasingly emphasized individual responsibility, rather than the importance of redressing health inequities via structural and institutional interventions.

As the CDC and other public health leaders have signaled the end of the pandemic by downplaying the risk of COVID infections, pandemic social programs have also ended, placing many communities at increased risk of poverty. The employment-based health insurance system leaves millions at risk of losing health coverage. BIPOC communities have also borne the brunt of COVID-related economic downturn and were more likely to have lost work and income due to the pandemic, more likely to have difficulty making rent and mortgage payments, and less likely to have paid sick leave.[80] Meanwhile, billionaires' wealth increased by $1.5 trillion (50%) during the pandemic while millions of Americans lost their lives and livelihoods.[80]

Recommendations to Address Root Causes of Health Inequities:

- **The CDC should partner with impacted communities and continue to leverage its authority and influence to enact and advocate for broader policies that directly address the social determinants of health**, including safe and affordable housing, universal health care, decarceration, improved workplace protections, living wages, and expanded paid leave and universal care infrastructure, such as childcare and increased support for family caregivers.

- **The CDC should publicly advocate for the COVID-19 Public Health Emergency measures to be made permanent and expanded upon**, including increased access to health insurance, paid leave, food stamps, improved ventilation, and COVID vaccines, testing and treatment, in order to address inequities and build a resilient public health infrastructure for this and future pandemics.

Conclusion:

In January 2023, White House Covid-19 response coordinator Ashish Jha warned that the U.S. health system will likely be dysfunctional due to COVID for years.[81] President Biden's plan to end the COVID-19 Public Health Emergency without making the vital public health measures it provided permanent will only worsen the inequities[82] and high rates of morbidity and mortality, which have marked the COVID-19 pandemic in the United States. Instead, the CDC should publicly advocate for the COVID-19 Public Health Emergency measures which expanded access to health insurance, paid leave, food stamps, improved ventilation, and COVID vaccines, testing and treatment, among others

to be made permanent and expanded upon in order to address inequities and build a resilient public health infrastructure for this and future pandemics.

If we fail to address the COVID-19 pandemic, we are accepting a worse quality of life overall, shorter life expectancy, and greater degree of suffering for great numbers of people,but we can choose another path. Instead, the People's CDC urges the CDC, national and local public health departments, school districts, and community leaders to embrace an evidence-based, community-care strategy to address the COVID-19 pandemic. This strategy should center people who are disproportionately vulnerable to the harms of the virus and be proactive, comprehensive, and precautionary. The CDC must use evidence-based, layered prevention and mitigation measures to control disease transmission and partner with communities and institutions to promote population health. As we witness the growing numbers of COVID deaths and people disabled by Long COVID, and emerging variants that can already evade existing vaccines and treatments, it becomes increasingly clear that a holistic, sustainable approach to the COVID pandemic is essential. The health of the U.S. economy is only as good as the health of the people who do the work, and a plan to protect everyone, especially the most vulnerable, will be better in the long term, for people, for the economy, and for future generations.

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