Assessing the HIV Community's Needs and Concerns About Long COVID

People with HIV experienced "significant pandemic stress," isolation, stigma and concerns about long COVID, according to a recent survey and report.

June 29, 2022 By Jilleen Barrett

COVID-19 and long COVID continue to impact people's lives, including those of people living with HIV. A recent survey, report and webinar assessed the HIV community's concerns regarding COVID-19 and offered community leaders recommendations for meeting the needs of the HIV population at this moment in history.

Titled "Resourcing the HIV Community to Face COVID and Long COVID in 2022," the report and webinar were presented by Strategies for High Impact, the Network for Long COVID Justice and Springboard Health Lab.

According to the report, the top-line recommendations are that the HIV sector should be resourced to:

- Ensure accurate and timely information, resources and best practices on COVID-19 across the HIV sector;
- Increase accessibility and expand disability justice in HIV community organizations, programs and practices; and
- Address long COVID and other complex chronic conditions in PLHIV [people living with HIV] and the HIV community, through programming, advocacy and communications.

Check out this report on resourcing the #HIV community for COVID & #LongCovid, a project by @LongCOVIDNatl, which NASTAD was proud to co-sponsor with over a dozen major HIV orgs. It summarizes a webinar, national survey, leadership meeting, & action steps. https://t.co/1NUCxipdIM pic.twitter.com/iOrprB3ikD

— NASTAD (@NASTAD) June 8, 2022

For the report, researchers conducted a digital survey between January and March, which drew 71 participants, 70.4% of whom reported that they were living with HIV.

“Participants reported significant pandemic stress,” states the report, “including concerns about long COVID (88.7%), the impact of COVID-19 infections in people living with HIV (89.9%), risks to HIV programs and funding (73.2%), increased stigma around viral infections (70.4%) and the impact of isolation on PLHIV (88.7%).”

The report includes several video segments, such as the testimony below from Philip Shubin about living with HIV and long COVID:

The report concludes that “HIV communities have a widespread need and eagerness for information, resources and support on a range of issues and concerns about COVID-19 and long COVID.” These include:

- Many consulted groups report that their leadership, staff and members/clients are unsure of the current recommendations for COVID-19 prevention, vaccination and treatment.

- The COVID-19 pandemic holds particular challenges for people living with HIV (PLHIV) and the HIV community, including retraumatization, as survivors of an ongoing viral epidemic; potential increased risk of severe or fatal COVID-19 due to comorbidities common among HIV long-term survivors; programmatic service disruptions; and potential adverse drug interactions if prescribed the most widely-used COVID-19 antiviral treatment, Paxlovid.

- PLHIV who experience frailty or other comorbidities and disabilities face a greater risk of isolation, which brings additional negative emotional, mental and physical health outcomes. As many people go back to pre-COVID-19 practices, those who remain vigilant in avoiding exposure may experience further marginalization and stigma.

- Increasing research evidence indicates that PLHIV may be at significantly higher risk of Long COVID, an umbrella term used to describe a range of potentially severe, chronic conditions in people following a COVID-19 infection, including those that initially manifest as asymptomatic or mild cases.

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“The HIV sector has much to teach our nation about tackling pandemics—including the importance of meaningful involvement of those most affected,” wrote the authors in the report’s introduction, adding that “increasing evidence indicates that PLHIV may be at significantly higher risk of long COVID.”

The report highlights the racial disparities that persist in both health crises, stating: “As the nation reaches the tragic marker of 1 million documented deaths from COVID-19, it is clear that the tragic losses of the pandemic have occurred—and continue to occur—much more heavily in the Black and Brown communities that also face disproportionate HIV rates.”

To learn more about these intersections and disparities, read the full report or join a live Zoom discussion about it on Thursday, July 14, at 3 p.m.

To learn more about the coronavirus and HIV, click #COVID-19. You’ll find articles such as “The HIV Movement Must Come Through,” an opinion piece by HIV activist JD Davids, who outlines how people with HIV can be good allies to those with long COVID. Davids also lists resources for those with long COVID. For more about the pandemic, visit POZ’s sister website COVIDHealth.com.

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