May 6, 2021

Office for Civil Rights
U.S. Department of Health and Human Service
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: Department of Health and Human Services, Office for Civil Rights RIN 0945-AA00, Docket Nos. HHS-OCR-2021-0006 and HHS-OCR-0945-AA00, Proposed Modifications to the HIPAA Privacy Rule

The Center for HIV Law and Policy (CHLP) is a national legal and policy resource and strategy center working to reduce the impact of HIV on marginalized communities and to secure the rights of people affected by HIV. We and the undersigned organizations welcome the opportunity to provide comments on the Department of Health and Human Services' (HHS) Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinate Care and Individual Engagement (Proposed HIPAA Rule) which was published in the Federal Register on January 21, 2021 (RIN 0945-AA00, Docket Nos. HHS-OCR-2021-0006 and HHS-OCR-0945-AA00).

CHLP and our allies oppose provisions of this proposal that would weaken the HIPAA Privacy Rule and we urge OCR not to adopt those provisions in a final rule. Specifically, we oppose the provisions that would: 1) permit covered entities to disclose PHI to avert a threat to health or safety when a harm is "serious and reasonably foreseeable," instead of the current stricter standard which requires a "serious and imminent" threat to health or safety; and 2) replace the privacy standard that permits disclosure of PHI based on "professional judgment" with a standard permitting such uses or disclosures based on a covered entity's "good faith belief that the use or disclosure is in the best interests of the individual."

These and other proposed changes are not based on actual evidence or data about the alleged weaknesses of the current privacy rule. Instead, they are based on anecdotes, stereotypes, and stigma around people with disabilities, particularly those with mental health conditions or substance use disorder (SUD). CHLP echoes the concerns of other disability rights groups on this failing.

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Indeed, while the proposed changes single out people with mental health conditions and SUD, they affect many people with other disabilities, including those living with chronic or infectious diseases. In view of the continuing illiteracy about the mechanisms of infectious disease, particularly HIV and viral hepatitis, that we encounter in our work, we believe that widening the Privacy Rule exceptions will only lead to further abuse and harm to people living with HIV (PLHIV) or hepatitis.

The release of personal, sensitive health information triggers particularly severe consequences for persons living with stigmatized and poorly understood infectious diseases. Due to disease criminalization laws,[1] people living with HIV, viral hepatitis, and even tuberculosis can be charged with a felony offense simply because they are unable to prove whether they disclosed their HIV status to sexual partners; felony penalties also are imposed for spitting or other behaviors that cannot transmit HIV.[2] A shocking number of Black men have been charged under these laws following encounters with police claiming contact with the arrestees' spit or other body fluids, often when there are allegations of excessive use of force during an arrest.[3]

A number of states have also singled out sex workers with HIV for harsher legal penalties as well.[4] As a consequence, solicitation charges that normally are treated as a misdemeanor become felony offenses, even when there has been no sexual contact. Data show that persons

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[1] *See generally, HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice*, Ctr. for HIV L. & Pol'y (2020), https://www.hivlawandpolicy.org/sourcebook; *U.S, Laws and Prosecutorial Tools*, Ctr. for HIV L. & Pol'y (2020), https://www.hivlawandpolicy.org/sites/default/files/U.S.%20HIV%20Laws%20and%20Prosecutorial%20Tools%2C%20CHLP%20%282020%29.pdf.

[2] *See, e.g.*, Brad Sears, Shoshana K. Goldberg & Christy Mallory, *The Criminalization of HIV and Hepatitis B and C in Missouri: An Analysis of Enforcement Data from 1990 to 2019*, Williams Inst. 3 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-MO-Feb-2020.pdf (In Missouri, for example, one in every sixty people living with HIV has been arrested under an HIV-specific law.); Amira Hasenbush, *HIV Criminalization in Florida*, Williams Inst. 10 tbl.2 (Oct. 2018), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-FL-Oct-2018.pdf (noting 874 HIV-specific charges in Florida across 614 people from 1986 to 2017); Amira Hasenbush, *HIV Criminalization in Georgia*, Williams Inst. 3, 8-9 (Jan. 2018), https://williamsinstitute.law.ucla.edu/wp-; Zita Lazzarini et al., *Criminalization of HIV Transmission and Exposure: Research and Policy Agenda*, 103 Am. J. Pub. Health 1350, 1351 (2013) ("In three US studies, approximately 20% to 25% of cases involved spitting, biting, or external exposure to bodily fluids that pose almost no transmission risk.").

[3] *See, e.g.*, Nathan Cisneros and Brad Sears, *Enforcement of HIV Criminalization in Nevada*, Williams Inst. 1-2 (May 2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-NV-May-2021.pdf ("Black people are 10% of Nevada's population and 28% of people living with HIV (PLWH) in the state, but 40% of those who have been arrested for HIV crimes,"); Amira Hasenbush, *HIV Criminalization in Georgia*, Williams Inst. 3 (Jan. 2018), https://williamsinstitute.law.ucla.edu/wp- (63% of people arrest under an HIV-related offense in Georgia were Black); Amira Hasenbush, *HIV Criminalization in California*, Williams Inst. 3 (May 2015) ("Black people and Latino/as make up two-thirds (67%) of the people who came into contact with the criminal justice system based on their HIV, although just half (51%) of people living with HIV/AIDS in California are Black and Latino/a.").

[4] Twelve states and U.S territories have specific offenses for sex work or solicitation while living with HIV. *U.S, Laws and Prosecutorial Tools*, Ctr. for HIV L. & Pol'y (2020), https://www.hivlawandpolicy.org/sites/default/files/U.S.%20HIV%20Laws%20and%20Prosecutorial%20Tools%2C%20CHLP%20%282020%29.pdf.

convicted under these laws overwhelmingly are Black women.[5] Such charges are possible because individuals who are arrested for solicitation often are involuntarily tested for HIV with results shared with law enforcement personnel; or this information is provided to prosecuting officials when requested, typically without a court order.

In Nevada, for example, if someone has previously been charged with prostitution and then tested for HIV (currently the standard practice there), as a matter of course the health department shares a positive test result with law enforcement officials, without a court order.[6] Because the test result becomes part of the criminal record, when a sex worker has subsequent contact with the criminal legal system, regardless of the context, an officer, attorney, judge or other third party knows that person's HIV status. Indeed, as the National Alliance of State & Territorial AIDS Directors (NASTAD) has found, state health department policies on requirements for release of HIV data for law enforcement purposes vary widely and frequently allow release without a court order.[7] With the expanded use of surveillance and research based on an individual's viral load and subsequent phylogenetic testing data, it is increasingly critical that HHS *tighten* criteria for the release of such data to state and federal prosecutors.

This criminalized framework under which PLHIV and others living with stigmatized infectious diseases must live, and any disclosure of PHI to law enforcement that comes as a result, have consequences even when sanctions are not imposed. Any contact with the criminal legal system can expose PLHIV to potential trauma, harm, and liability. Law enforcement officers, for example, may invoke HIV criminal laws as grounds to threaten, detain, or arrest individuals they encounter following disclosure of an individual's HIV status. During plea bargaining, prosecutors can also upcharge, or wield the threat of charges against, PLHIV in order to pressure them into accepting criminal pleas. And finally, when people are arrested or charged under these laws their name, picture, and HIV status frequently are made public or shared with the media, which

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[5] Amira Hasenbush, *HIV Criminalization in Florida*, Williams Inst. 2-3 (Oct. 2018), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-FL-Oct-2018.pdf "(Convictions for HIV arrests were twice as likely when there was a concurrent sex work arrest than when the HIV offense occurred outside of the context of sex work. In HIV offenses involving sex work, Black women were significantly more likely to be convicted for the disease-specific offense and significantly less likely to be released without a conviction than all other groups. Black men were more likely to be convicted of an HIV-related offense than White men and White women."); Amira Hasenbush, *HIV Criminalization in Georgia*, Williams Inst. 2 (Jan. 2018), https://williamsinstitute.law.ucla.edu/wp- (convictions for HIV arrests were three times as likely when there was a concurrent sex work arrest, which were more likely to involve Black women); Nathan Cisneros and Brad Sears, *Enforcement of HIV Criminalization in Nevada*, Williams Inst. 1-2 (May 2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-NV-May-2021.pdf (In Nevada, "the majority of arrests for HIV crimes involve sex work. Nevada's HIV crimes specific to sex work account for 61% of all HIV-related charges, and 64% of all convictions.").

[6] Testimony to the Nevada State Assembly Committee on Health and Human Services (May 3, 2021), http://sg001-harmony.sliq.net/00324/Harmony/en/PowerBrowser/PowerBrowserV2/20210503/-1/?fk=8472&viewmode=1 (beginning at 2:32:30).

[7] *HIV Data Privacy and Confidentiality Legal & Ethical Considerations for Health Department Data Sharing*, NASTAD 5-6 (June 2018); https://www.nastad.org/sites/default/files/Uploads/2018/nastad-hiv-data-privacy-06062018.pdf.

further stigmatizes them.[8] The collateral consequences of contact with the criminal legal system are wide ranging and long lasting. With few if any legitimate bases for criminal action based on an individual's health status, HHS should be exploring approaches to *increase* barriers between health information and law enforcement authorities.

With the development of effective antiretroviral therapies, PreP, and PeP, the risks and consequences of HIV transmission are quite different than they were a decade ago.[9] Unfortunately, education about and awareness of this evidence among providers, in the criminal legal system, and in our communities as a whole have not kept up.[10]

Particularly where analysis of what constitutes a serious threat or risk comes into play, we see over and over again that people in positions of authority - whether medical or service providers or law enforcement officials - make decisions based on inaccurate information and stereotypes that betray the privacy of and do lasting harm to PLHIV. This is particularly true when the patient is a person of color, an LGBTQ person, or a sex worker, where stereotypes and marginalizations are multiplied. Too many providers - and too many parts of the criminal legal system - see marginalized people with HIV as inherently dangerous and predatory.[11] Thus we believe that lowering the threat level needed for a provider to disclose HIV status from "imminent" to "reasonably foreseeable," will lead to many unnecessary and baseless disclosures.

There is no way to unring the bell when a person's HIV or infectious disease status is made public, and there are limited ways to hold anyone responsible for wrongful disclosure,

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[8] Interestingly, while living in a state with an HIV criminal law is not shown to increase HIV testing rates, media reporting of criminalization was associated with a *decrease* of HIV testing rates in states with HIV exposure laws. Sug Goo Lee, *Criminal law and HIV testing: empirical analysis of how at-risk individuals respond to the law*, 14 Yale J Health Policy Law Ethics 194 (2014). *See also Media-driven stigma continues with new HIV criminalization case*, Aids Foundation Chicago (Oct. 2014), https://www.aidschicago.org/page/news/all-news/media-driven-stigma-continues-with-new-hiv-criminalization-case.

[9] *See e.g.*, Evidence of HIV Treatment and Viral Suppression in Preventing the Sexual Transmission of HIV, Ctrs. for Disease Control & Prevention (May 6., 2021), https://www.cdc.gov/hiv/risk/art/evidence-of-hiv-treatment.html.

[10] *See, e.g.*, Avy Skolnik et al. *Roadblocks to PrEP: What Medical Records Reveal About Access to HIV Pre-exposure Prophylaxis*, 35 J GEN INTERN MED 832 (2020); Dawn K. Smith et al., *PrEP Awareness and Attitudes in a National Survey of Primary Care Clinicians in the United States, 2009–2015*. PLoS One 11(6), https://doi.org/10.1371/journal.pone.0156592; Shilpa Hakre et al. *Knowledge, attitudes, and beliefs about HIV pre-exposure prophylaxis among US Air Force Health Care Providers*, 95 Medicine e4511: (Aug. 2016).

[11] *See, e.g.* the case of Nushawn Williams in New York State. The 1997 case of Nushawn Williams, a 19-year-old Black man who was accused of having sex with younger women while he was HIV positive, sparked an extraordinary amount of sensationalist media coverage describing Williams as a predator and a monster. Despite the fact that he completed his original sentence in 2010, Williams remains confined under state civil commitment laws as a "dangerous sex offender" based almost entirely on the fact that he was sexually active while HIV positive. *Nushawn Williams Case Background and Talking Points*, Ctr. for Hiv L. & Pol'y (2021), https://www.hivlawandpolicy.org/resources/nushawn-williams-case-background-and-talking-points-chlp-updated-2021; *see also* Stephanie Pappas, APA, *HIV laws that appear to do more harm than good,* 49 Monitor on Psychol. 32 (Oct. 2018).

particularly when PHI is disclosed by law enforcement or court officials who are not covered by HIPAA. Lowering the standard from "professional judgement" to a presumption of "good faith," will limit consequences for wrongful disclosure even further. Assuming "good faith" by providers is a paternalistic standard based on an idea that providers always know and do best, and are not affected by stereotypes, stigma, and inadequate education of the science behind disease transmission. This is simply not true.

The flurry of punitive proposals in response to the COVID-19 epidemic[12] make it clearer than ever that we need greater, not diluted, privacy protections for sensitive personal health information, particularly where infectious diseases are involved. Even without the pending proposal, the current exceptions to privacy afforded to law enforcement are routinely abused, and largely unsupportable from either a public safety or public health perspective. Weakened disclosure rules and criminalized outcomes are at direct odds with individual and public health goals. Allowing providers to make more disclosures with lower standards under the proposed changes to the HIPAA Privacy Rule can only make this situation worse.

We thank you for your consideration of our comments and concerns.

Respectfully submitted,

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[12] Pascal Emmer et al., *Unmasked: Impacts of Pandemic Policing*, COVID-19 Policing Project (Oct. 2020). https://communityresourcehub.org/wp-content/uploads/2020/12/Unmasked.pdf. *See also* Memorandum from the Deputy Attorney General on Department of Justice Enforcement Actions Related to COVID19 (March 24, 2020), https://www.justice.gov/file/1262771/download; *An Act concerning making terroristic threats concerning infectious disease and amending N.J.S.2C:12-3*, S. 2361, 219th Leg., Reg. Sess. (N.J. 2020), https://legiscan.com/NJ/text/S2361/id/2178616.

Advocating Opportunity

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