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Acting Director
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 No. OCR-OCR-0945-AA00

Dear Acting Director Frohboese:

The National Center on Domestic Violence, Trauma and Mental Health and the National Network to End Domestic Violence are submitting these comments in response to the Proposed Modifications to the HIPAA Privacy Rule to Support and Remove Barriers to Coordinated Care and Individual Engagement by the Department of Health and Human Services (HHS) and Office of Civil Rights (OCR). The National Center on Domestic Violence, Trauma and Mental Health (NCDVTMH) is the U.S. HHS, Administration on Children, Youth and Families, Family and Youth Services Bureau, Family Violence Prevention and Services Program, Special Issue Resource Center dedicated to addressing the intersection of domestic and sexual violence, trauma, substance use, and mental health. NCDVTMH enhances agency- and system-level responses to survivors and their families through comprehensive training and technical assistance, research and evaluation, policy development, and public awareness. NCDVTMH offers training and consultation to domestic violence and sexual assault advocates, programs, and coalitions; healthcare, mental health, and substance use disorder treatment providers; legal and child welfare professionals; and local, state, and federal policymakers. The National Network to End Domestic Violence (NNEDV) was founded more than 25 years ago to be the leading voice for survivors of domestic violence and their allies. Today, NNEDV provides training and assistance to the statewide and territorial coalitions against domestic violence. It also furthers public awareness of domestic violence and changes beliefs that condone intimate partner violence.

NCDVTMH and NNEDV echo the Consortium for Citizens with Disabilities in strongly opposing key provisions of this proposal that would weaken the HIPAA Privacy Rule and also urge OCR to not adopt those provisions in its final rule. These include OCR's proposals to: (1) eliminate the requirement that professional judgment be exercised in determining whether disclosure is warranted without an individual's consent under five exceptions to privacy protections, (2) add a presumption under these exceptions that any use or disclosure of protected health information was done in "good faith," (3) remove the requirement that harm must be serious and imminent under the "dangerousness" exception, (4) add a presumption to the dangerousness exception that the harm was sufficient to warrant use or disclosure of protected health information, (5) add a requirement that heightened



deference be given to the decisions of mental or behavioral health professionals or other providers with “specialized training, expertise, or experience in assessing an individual’s risk to health or safety” to invoke the dangerousness exception, and (6) remove the “minimum necessary” standard for disclosures for individual-level care coordination and case management as well as broadening the allowance of disclosures to third parties.

In our comments, we specifically want to highlight concerns about the proposed changes that are likely to increase the level of risk and danger for people who experience domestic violence, sexual assault, and stalking.

Potential Risks to Survivors of Domestic Violence Associated with Proposed HIPAA Protection Waivers

Although loosening HIPAA protections is designed to improve efficiency in both patient care and public health responses, disclosure of information to an abusive partner poses risks to survivors. These changes are highly problematic for survivors of domestic violence (DV), sexual assault, and stalking for a number of reasons.

- People who abuse their partners attempt to use any information provided to further their control (e.g., threatening to cut off a survivor’s health insurance, threatening loss of custody based on a survivor’s health, mental health, or substance use condition (including COVID-19 exposure or vaccine status), and actively using PHI against a partner in custody battles.
- Privacy changes that increase an abusive partner’s ability to access information about a DV survivor’s location, disclosure of abuse, treatment, medication use, substance use, or other details about their health can increase a survivor’s danger and compromise their health and safety.
- Failure to honor requests to opt out of a facility directory, requests to invoke privacy restrictions, or requests to keep communications confidential can put survivors at risk by increasing the likelihood that their information may be disclosed to an abusive partner or someone associated with that individual.
- Failure to disclose the limits of privacy and confidentiality is particularly problematic for survivors of domestic violence, sexual assault and stalking, who need to be able to weigh potential risks to their safety and make informed decisions regarding their care.

1. Loosening standards required for disclosure of personal health information (PHI)

First, we are opposed to the proposed changes that involve eliminating “professional judgment” and presuming a “good faith” belief to invoke exceptions to privacy protections. Such language is designed to decrease administrative burden and accountability for healthcare systems, at the cost of patient privacy and choice, which is particularly dangerous to survivors of domestic violence, sexual assault, and stalking. There must be strong standards of accountability and safety built into any information sharing practices, with the patient’s well-being at the center, particularly in circumstances where non-consensual information sharing must occur.

We are particularly concerned about disclosure of information to intimate partners and other family members and increasing partner and family involvement in an individual’s health, mental health and/or substance use disorder treatment. While this may be appropriate in some circumstances, the involvement of family members and/or intimate partners in an individual’s healthcare, mental health care and/or SUD treatment creates unique risks for survivors of domestic violence, whose partner or family member(s) may be perpetrating domestic violence or child abuse. For safety reasons, including

fear of retaliation, a survivor may not want their abusive partner to have access to their personal health information. In some cases, the fact that a survivor has sought help at all might put that individual at risk of retaliation. The possibility of family involvement may cause survivors to delay seeking needed health, mental health or SUD services—or go entirely without services—for fear their sensitive information will be shared. At a minimum, health, mental health, and substance use disorder treatment providers making these decisions must be sufficiently trained and prepared to assess for domestic violence and other forms of intrafamilial abuse and to engage in DV-informed consent processes with their patients, prior to sharing information with a family member or involving a family member in a patient’s care. Lowering the current HIPAA standard from “professional judgment” to “good faith” makes it even less likely that a provider will be sufficiently knowledgeable and more likely that stigma and stereotypes regarding DV, mental health, and substance use will come into play.

Based both on our research and on reports from DV survivors and service providers, many survivors experience coercive tactics specifically related to their health, mental health, and use of substances as part of a broader pattern of abuse and control. A pair of studies by NCDVTMH and the National Domestic Violence Hotline on mental health and substance use coercion found disturbingly high rates of abuse specifically targeting a partner’s mental health and/or substance use. Callers reported that their abusive partners intentionally undermined their sanity; coerced them into using substances, prevented them from accessing treatment, controlled their medication; sabotaged their recovery efforts; and then used their mental health or substance use “condition” to discredit them with friends, family, helping professionals, and the courts. Callers also reported that abusive partners would try to insinuate themselves into the treatment process, control providers’ perceptions, and gather information that could be used to jeopardize a survivor’s employment, housing and/or ability to maintain custody of their children and keep them entrapped in the relationship. Experiencing a mental health or substance use disorder places people at greater risk for being controlled by an abusive partner. Stigma associated with substance use and mental illness contributes to the effectiveness of these abusive tactics and can create additional barriers for survivors and their children when they try to seek help.

Additionally, when processes for obtaining patient consent become perfunctory in practice, they fail to adequately protect patient safety and choice. The need for a robust informed consent process accompanying solicitation of consent to share personal health information has been increasingly critical, particularly in the context of modern era of EHRs.

2. Overly crediting the ability of mental health providers to predict dangerousness and suicidality

Again, part of the justification for loosening criteria for sharing PHI is based on the idea that doing so could reduce dangerous outcomes (i.e., suicide, homicide). As noted in the CCD comments, research shows that mental health providers are not able to accurately predict future violence or suicidality. Using this as a justification for reducing privacy protections is not justifiable. In addition, we do know that people who abuse their partners routinely try to manipulate the perceptions of mental health providers as a way to discredit their partners and justify their abuse. Common tactics include coercing a partner to take an overdose and then, calling a suicide prevention hotline and trying to have them committed to a psychiatric institution; claiming a partner was dangerous and “out of control” due to substance use or mental illness as a way to justify physical restraint and violence; coercing a partner to use substances, videotaping them, and presenting the videotape to child protective services. Too often, health, mental health and substance use disorder treatment providers are not be aware of these forms

of abuse and may be deceived by the seeming concern of a partner or family member whose primary goal is to exert control over their patient.

3. Proposed changes related to care coordination

The proposed care coordination changes raise additional concerns based on trends we are seeing related to online referral software systems. Much of care coordination relies on a system of sharing designed to “close the loop”. Victim service providers funded under VAWA, FVPSA, and VOCA cannot participate in such a system of sharing. While information can certainly be shared with them by healthcare providers with the consent of the survivor, healthcare providers should not expect such sharing to be reciprocal in nature. In other words, victim service providers cannot be expected to provide information to the healthcare provider, as this would be in violation of the strict obligations under VAWA, VOCA, and FVPSA. The only time such information could be shared with a healthcare provider is if the *survivor* explicitly requests it to help meet their personal goals and provides written, time-limited, consent.

The premise that providers know best and should be able to refer someone for services without first having a conversation with them and receiving consent to share their information is paternalistic and particularly dangerous for survivors of DV, sexual assault and stalking. The proposed changes appear to be centered on reducing the administrative “burden” healthcare providers experience when they are required to obtain explicit consent from a patient before sharing their information with a social service organization. This devalues the importance of patient privacy, patient choice, and decision-making. Such devaluing of privacy and choice is of particular concern to survivors of domestic violence, sexual assault, and stalking and their children, where information sharing can lead to grave physical, financial, and emotional harm, and even death. Patients are best equipped to decide what information is and isn’t safe for them, and as such, should be consulted any time PHI will be shared with social service organizations outside of the healthcare system.

The domestic violence field has worked hard to ensure that, under HIPAA, survivors have the right to request privacy restrictions and confidential communications to prevent abusive partners from accessing information about their health or mental health care. For survivors of domestic violence, safety often depends on robust informed consent and disclosure of the least amount of information, possible. As part of informed consent to treatment discussions with patients, HIPAA should require health care practitioners talk with patients about potential risks associated with disclosure of their PHI. These risks include the possibility that an abusive partner who works within the healthcare system, for an entity covered by the consent-to-treatment agreement, or who is otherwise able to access their record online (e.g., through spyware or coercing a partner to share passwords), might be able to access sensitive information about them and their treatment. Frank discussions about these and similar risks are particularly critical for providers who are not already sensitive to these issues.

For more information, see NCDVTMH’s [Coercion Toolkit](#), [NCDVTMH and NNEDV’s Electronic Health Records: Privacy Considerations for Domestic Violence & Sexual Assault Advocates](#), NNEDV’s [Confidentiality Toolkit](#), and [Futures Without Violence’s Summary of HIPAA Privacy Protections for Victims of Domestic Violence](#).

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