

ACMHA ARM CHAIR REFLECTIONS

The Balancing Act of Protecting Substance Use Record Confidentiality

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In 1972, Congress adopted the federal Confidentiality of Alcohol and Drug Abuse Patient Records law. This statute reflects Congress's longstanding concern that individuals not be made more vulnerable as a result of seeking treatment for a substance use disorder. The reality of stigma and discrimination remains just as real today as it was in 1972. It remains crucial to continue to protect the privacy of people who seek treatment for addictions.

An initiative to modernize the federal substance use record confidentiality regulations has been undertaken by a coalition of diverse stakeholders, the Patient Protection Coalition. The Coalition and the debate that it has sparked throughout the substance use and mental health fields have focused on rebalancing protections against discrimination from disclosure of sensitive substance use treatment information and the need for efficient sharing of health information for safe and effective care. These very real and very urgent problems are in need of resolution.

What was a simple and correct solution to protect the privacy of substance use treatment information 37 years ago needs to be reformulated to be simple and correct in the current environment. Many forces are disrupting the stability that the federal substance use privacy regulations created in managing substance use treatment information. Integrated health and behavioral health care, involvement of primary care and medical specialists in treating and managing substance use, growing use of electronic medical records and electronic data exchanges, parity, and national health reform are generating uncertainty and conflicts about managing substance use treatment information.

Under the existing federal law, except in cases of medical emergency, a patient has a right to decide what, if any substance use disorder treatment information is disclosed to his or her health care providers. This current right requires the patient to specifically authorize the disclosure in the form of a written consent (as specified by 42 CFR 2.31) except in cases of medical emergency (42 CFR 2.51).

Some privacy advocates believe the patient's right to affirmatively consent should be maintained, even for disclosures to other health care providers providing treatment to the patient, even though this is not required under the HIPAA privacy regulations.

On the other side of the patient protections, debate health care providers advocate for the need for relevant information, including substance abuse disorder treatment information, to

appropriately diagnose and treat patients. Physicians have explained that a non-medical professional might not understand or recognize how certain information may impact a physician's course of testing, diagnosis, treatment and plan of care. Without complete information, the course of treatment could adversely interact with existing medications, exacerbate other underlying health conditions or, worse yet, jeopardize the life and safety of the patient.

The Patient Protection Coalition and more than 40 substance use and mental health organizations have called for SAMHSA to lead a deliberative process to explore perceived problems in protecting sensitive substance use treatment information and improving patient safety and health; to determine the cause of the problems; and to create practical, understandable solutions. The consensus process should address what information can be shared, with whom, for what purposes, with what permissions, and with what penalties for unauthorized disclosures. Special privacy and permission issues of parents and adolescents in substance use treatment must be considered.

A wide philosophical and value spectrum exists about the ultimate ownership and control of health information. At one pole are strong privacy advocates, current federal substance use privacy regulations, and many states' mental health and addiction privacy laws. From this perspective, patients should own and control their health data (with a few exceptions).

At another pole are advocates of patient-centered medical homes and many physicians and other health care providers who argue that immediate access to health data is necessary for good, safe care. At this pole is HIPAA, which gives the patient very limited control over their health data if used for the purposes of treatment, payment, or health plan operations.

Diverse and inconsistent state privacy laws governing substance use and mental health information further complicate the challenges of balancing privacy and data sharing.

A solutions-focused consensus process is needed that centers on interactions between clinicians, specialty substance use treatment providers and general medical programs, people in recovery, and families impacted by substance use of a family member. Advocates, lawyers, software vendors, academics and others have valuable expertise to contribute to the consensus process, but solutions must work for health care providers and consumers. Solutions may involve improved education of patients and providers, better execution within existing regulations, re-interpretation of the statute, or new legislation.

The initial focus of the Patient Protection Coalition was on protecting the privacy of sensitive substance use information and permitting limited sharing of health data governed by 42 CFR Part 2. In the February draft statute, the Patient Protection Coalition proposed several specific solutions (http://www.law.virginia.edu/pdf/faculty/bonnie_patientprotection.pdf):

- Permits very limited disclosures of information about substance use disorder treatment to health care providers and health plans for purposes of treatment, coordination of care, quality improvement, disease management and payment.
- Reiterates the requirement in the HITECH Act that HIPAA-covered entities and business associates must honor an individual's request to restrict disclosure to a health plan if payment for services is made out of pocket.

- Prohibits use of substance use information by a health plan for discriminatory purposes.
- Permits disclosure to health providers or health plans without patient authorization only demographic information, diagnosis, medications, laboratory results, identification of past or current treatment providers, and dates of services.
- Applies a “minimum necessary” standard to any disclosure of alcohol/drug program patient records. Psychotherapy notes and progress notes are specifically excluded. If more detailed information is needed, written consent will be required.
- Recognizes that even these limited disclosures could create a risk of improper use of the information and that the current federal statute and regulations are silent on a number of necessary patient protections. The draft proposal includes robust provisions to address these fundamental vulnerabilities: (1) prohibits discrimination on the basis of information in substance use disorder program records, (2) limits use in criminal and civil investigations or proceedings, (3) strengthens civil and criminal sanctions against unauthorized disclosures, and (4) gives individuals the right to pursue civil remedies against persons who violate this statute.
- Extends HITECH Act’s significantly increased penalties to any recipient of confidential substance use program information. Individuals whose records are unlawfully used or disclosed the right to bring a civil action in federal court to obtain an injunction and/or monetary damages. It requires payment of costs, including attorney’s fees to a patient that prevails in such a case. If an unauthorized use or disclosure was the result of willful, knowing or reckless actions, exemplary damages are required.

The current federal substance use privacy regulations only apply to information collected by specialized substance use treatment programs as defined by the regulations. But increasingly, substance use diagnostic and treatment information is recorded in medical records by physicians and other health care providers not covered by 42 CFR Part 2. For example, primary care physicians, including physicians delivering office-based opiate treatment; emergency medical personnel providing substance use screening, brief intervention and treatment (SBIRT); clinicians working in inpatient dual diagnosis programs; and residents being trained to deliver integrated SBIRT medical services are recording substance use diagnosis and treatment information in electronic medical records protected only by HIPAA. Clear guidance is needed to protect people seeking treatment for addictions from disclosure of sensitive health information and to permit sharing of information between health care providers needed to effectively and safely treat their addictions and other illnesses. The absence of privacy protections for substance use information in settings not covered by 42 CFR Part 2 is one of the most pressing reasons for a thorough review of substance use privacy regulations.

The consensus process should fit within the broader health information technology and electronic health record environment being led by the Office of the National Coordinator. Protections of sensitive substance use information should be consistent with protections for other sensitive information, including conditions for sharing information without patient consent, penalties for disclosure, and technological solutions.

We look to SAMHSA to provide leadership in facilitating an active consensus process to develop practical solutions that work for people in recovery, health care providers, and families. The consensus process that SAMHSA convenes should involve medical professions, health care organizations and health plans that are outside the substance use treatment programs covered by 42 CFR Part 2. The input from legal, software, privacy and policy experts will also be valuable

in the consensus process, but consumers and clinicians must be central. The substance abuse record confidentiality is a problem that needs resolution now, and the proposed consensus process would generate effective and balanced solutions.