



People with addiction issues should be able to control their own health data

BY PATRICK J. KENNEDY AND KEVIN SCALIA, OPINION CONTRIBUTORS — 01/11/18 05:00 PM EST
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Much of the discussion about the concurrent opioid and suicide epidemic in our nation centers on the need for increased funding and resources. However, another major hurdle we face involves decades-old federal health record privacy regulations containing complicated, cumbersome

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consent requirements that discriminate against and endanger people with a substance use disorder (SUD) or history of SUD treatment.

People with diabetes, asthma, HIV, cancer or a history of heart attack can easily share their health information with doctors. They can also take full advantage of electronic health information exchanges (HIEs) that reduce the risk of potentially deadly medication errors among care teams.

Why should it be any different for a person with a history of SUD? Why are brain diseases excluded from a comprehensive, collaborative approach to care?

The ultimate goal of consent should be to give people the power to share their own health data with healthcare providers, if they so desire. This power of consent should apply regardless of whether a person has a SUD, mental illness, cancer, diabetes or multiple co-occurring conditions. Likewise, if a person does not wish to share her health data, she should have the clear option to either opt-out or not opt-in to sharing that information.

Current [federal privacy regulations \(42 CFR Part 2\)](#), which only apply to people with a SUD, place restrictions on sharing your own health data with a history of SUD. Such regulation puts a burden on patients, their treating providers, and Health information exchange (HIEs), making it operationally expensive — and with today's existing HIE technology — extremely costly, to transfer and manage SUD data.

This makes it very easy for HIEs to just say no, we will not accept your SUD data — thereby denying a person with SUD who wants to share data the same access to care as a person with cancer or diabetes. In this case, the regulations are discriminatory, preventing people with a SUD from benefiting from coordinated, integrated care, and increasing the chance of inappropriate opioid prescribing.

Imagine you are scheduled for outpatient surgery at a local surgery center. You sign a consent form for your SUD treatment program to share information about your addiction to OxyContin with the surgery center. The surgery center makes a note in your health record, but your surgeon,



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who is employed at a separate clinic, isn't permitted to see that part of your health record and prescribes OxyContin post-op for your pain.

Incidents like this happen every day across the nation, and raise several major concerns:

Incomplete health record information

Despite recent updates to regulations by the Substance Abuse and Mental Health Services Administration (SAMHSA), there are still significant complexities in one's ability to consent to release SUD treatment information to treating providers. This data gap prevents doctors and others from seeing a full picture of their patient's health, substantially increasing the risk of treatment and prescribing errors.

Discrimination and lack of parity

Addiction is a disease, not a mindset or a moral failing. Outdated Part 2 regulations are aiding and abetting discrimination against people with a SUD.

Technology limitations

Some integrated healthcare delivery systems, such as HIEs, Medicaid Health Homes and Medicare Accountable Care Organizations (ACOs) won't accept a patient's data (who has a history of SUD treatment) because they lack the technology or financial resources to comply with current consent and data segmentation requirements. Ironically, these entities were designed to provide "whole-person" care that addresses a full spectrum of co-occurring brain and body health conditions, including addiction treatment.

What's the answer?

We are seeing some movement in the right direction. There are indications that SAMHSA may reopen the rulemaking process for further input. Reps. Markwayne Mullin (R-Okla.) and Earl Blumenauer (D-Ore.) have introduced the bipartisan Overdose Prevention and Patient Safety Act in the U.S. House. A bipartisan companion bill, the Protecting Jessica Grubb's Legacy Act (The Legacy Act), has been introduced in the U.S. Senate by Sens Joe Manchin (D-W.Va.) and Shelley Moore Capito (R-W.Va.).

These bills more closely align 42 CFR Part 2 regulations with HIPAA, helping to ensure that all clinicians involved in a person's care get the full picture of their health. The bills also strengthen protections and prohibitions against disclosures of SUD information for criminal justice purposes — a legitimate concern of patient advocacy groups.

Most recently, during the fourth meeting of the President's Commission on Combating Drug Addiction and the Opioid Crisis, leaders from the nation's top insurance companies, as well as Commission members, overwhelmingly called for immediate 42 CFR Part 2 reform to stop the horrific cycle of preventable and unnecessary deaths in this country.

Recently, SAMHSA published a final rule that now allows for greater flexibility in the sharing of SUD treatment information by third parties for payment and healthcare operations. The final rule specifically excluded treatment, diagnosis and referral for treatment from the new, more flexible provisions.

Ironically, it's now easier for a person's SUD-related health information to be shared by payers, health plans and other entities for billing, payment, claims management and collections — than with the person's own healthcare providers for fully-informed diagnosis and treatment. The exclusion of treatment from the list of permissible activities for disclosure prevents people with an SUD from benefiting from coordinated, integrated care and exacerbates the stigma often associated with SUDs.

While HIPAA provides substantial protections for health information, it also provides something that Part 2 regulations cannot: patient choice. The decision to share critical health information should lie with the individual, not the Part 2 program, SAMHSA or the healthcare system.

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