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RPTR BRYANT

EDTR SECKMAN

IMPROVING THE COORDINATION AND QUALITY OF SUBSTANCE USE DISORDER TREATMENT

TUESDAY, MAY 8, 2018

House of Representatives,

Subcommittee on Health,

Committee on Energy and Commerce,

Washington, D.C.

The subcommittee met, pursuant to call, at 1:05 p.m., in Room 2123, Rayburn House Office Building, Hon. Michael Burgess, M.D. [chairman of the subcommittee] presiding.

Present: Representatives Burgess, Guthrie, Barton, Blackburn, Latta, Lance, Griffith, Bilirakis, Long, Bucshon, Brooks, Mullin, Hudson, Collins, Carter, Walden (ex officio), Green, Engel, Matsui,

Castor, Sarbanes, Kennedy, Eshoo, Degette, and Pallone (ex officio).

Staff Present: Mike Bloomquist, Staff Director; Daniel Butler, Staff Assistant; Zachary Dareshori, Legislative Clerk, Health; David DeMarco, IT Staff; Paul Edattel, Chief Counsel, Health; Ed Kim, Policy Coordinator, Health; Caprice Knapp, Fellow, Health; Drew McDowell, Executive Assistant; James Paluskiewicz, Professional Staff, Health; Kristen Shatynski, Professional Staff Member, Health; Jennifer Sherman, Press Secretary; Austin Stonebraker, Press Assistant; Hamlin Wade, Special Advisor, External Affairs; Jeff Carroll, Minority Staff Director; Waverly Gordon, Minority Health Counsel; Tiffany Guarascio, Minority Deputy Staff Director and Chief Health Advisor; Samantha Satchell, Minority Senior Policy Analyst; and C.J. Young, Minority Press Secretary.

Mr. Burgess. The Subcommittee on Health will now come to order. The chair recognizes himself for 5 minutes for the purpose of an opening statement.

Over the past several months, this subcommittee has held hearings to evaluate bills to address the opioid epidemic. We have also favorably reported 57 bills to the full Energy and Commerce Committee. Today, we are here to discuss a bill that would make timely reforms to a privacy law that affects patient access to healthcare and creates, in some minds, barriers to treatment: the Overdose Prevention and Patient Safety Act.

This hearing is an important opportunity for us to gain a better understanding of Federal privacy laws and how they function in the healthcare system. As a physician, I believe that it is vital that when we are making clinical decisions, you need all the appropriate information to make the correct determination in the treatment of the patient.

Suffering from a substance use disorder should receive the same level of treatment and care as other individuals. Patients affected with substance use disorder deserve to be treated by physicians who are armed with all the necessary information to provide the best of care. I certainly do understand and respect that privacy protection is paramount and should be held to the highest regard.

The Overdose Prevention and Patient Safety Act maintains the original intent of the 1970 statute behind 42 CFR part 2 by protecting patients and improving care coordination. In fact, Mr. Mullin's bill increases protections for those seeking treatment by more severely penalizing those who breach that patient data standard.

The issue of the stigma associated with substance use disorder has been a constant in all the discussions we have had, both in our offices and in hearings. We have dedicated months of our time to putting together legislation to help break the stigma and help individuals with this complex disease gain access to healthcare and support services critical to getting them on the road to recovery.

The first step in addressing this problem is admitting that it exists. If we continue to silo the substance use disorder treatment information from a select group of patients rather than integrating it into medical records and comprehensive care models, it is hard to see how we can ensure that these patients are receiving quality care.

Physicians, unknowing of a patient's substance use disorder, may prescribe medications that have significant drug interactions, or worse, they may prescribe controlled substances and make the patient's substance use disorder significantly worse. As it currently stands, 42 CFR part 2 is actively prohibiting physicians from ensuring proper treatment and patient safety while perpetuating stigma.

At our second opioid hearing held this March, we brought this bill up for consideration and openly debated the privacy concerns with experts and expert witnesses and the Health Subcommittee members. Additionally, panelists at our recent roundtable discussion with families who had been affected by the opioid epidemic echoed the need for reforming current law.

As we all know, providing high-quality healthcare is a team effort. Physicians do lead that team, but it is necessary that physicians have the necessary information to adequately coordinate care. We must align payment operations and treatment to allow coordination of both behavioral and physical health services for individuals with substance use disorder.

I recently heard from a hospital in my district that mentioned that there is some likelihood that part 2, as it currently stands, could be a disincentive for healthcare systems seeking to open additional addiction treatment centers due to the problems that the law creates, particularly the sequestration of patient information from their hospital.

There is a reason why the Substance Abuse and Mental Health Services Administration and most of the health stakeholder community is asking for this change. Clearly, there is an issue here that must be addressed. This crisis, this opiate crisis, is devastating our

country. Our action is important to the families and communities and to our constituents who are impacted by this epidemic.

I want to thank all of our witnesses who are here today and look forward to their testimony. And I will yield the balance of my time to the gentlelady from Tennessee.

[The prepared statement of Mr. Burgess follows:]

******** COMMITTEE INSERT ********

Mrs. Blackburn. Thank you, Mr. Chairman.

And I thank you for having this hearing and for listening to us as we have brought the concerns forward with part 2. This is something that has become a barrier to many people that are in treatment to get the full access to comprehensive care that they need to be able to fully recover.

And I have spent a good bit of time the past few years doing roundtables and visiting treatment centers and talking with families that are covered -- and I come at this as a mother and a grandmother and a friend, and having individuals close to me who have those in their family, in their circle that have suffered from addiction.

So thank you for this. Thank you for the attention to this issue. I look forward to the hearing.

I yield back.

[The prepared statement of Mrs. Blackburn follows:]

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Mr. Burgess. The gentlelady yields back.

The chair yields back. The chair recognizes the ranking member of the subcommittee, Mr. Green of Texas, 5 minutes for your opening statement, please.

Mr. Green. Thank you, Chairman, for holding today's hearing on substance use disorder treatment and 42 CFR part 2.

Ranking Member Pallone and I requested a hearing on 42 CFR part 2 last month, and I appreciate the majority's willingness to hold a hearing on this important issue. Title 42 of the Code of Federation Regulations part 2 are the implementing regulations of the two laws Congress passed in the early 1970s to protect individuals who seek treatment for substance abuse.

According to the Substance Abuse and Mental Health Administration, SAMHSA, the purpose of 42 CFR part 2 is to ensure that a patient receiving treatment for a substance use disorder in the part 2 program is not made more vulnerable by reason of the availability of their patient record than an individual with substance use disorder who does not seek treatment.

I agree with SAMHSA. Americans suffering from substance abuse should not become more vulnerable for doing the right thing and seeking treatment. 42 CFR part 2 provides individuals receiving substance use disorder treatment with the privacy they need to guard against the

negative consequences of unauthorized release of their drug or alcohol patient information, such as the loss of child custody, parental rights, the loss of a job, denial of healthcare, possible exclusion from public housing, possible criminal justice consequences, including arrest and prosecution.

SAMHSA in recent years has revised part 2 in order to improve coordination among providers providing treatment to individuals suffering from substance abuse.

The provisions expand the ability of providers to share information about a patient with a substance use disorder as well as allow new consent options for disclosure but continue to maintain part 2's core protections.

In 2017, treating provider relationships were allowed under certain circumstances, such as providing information to entities that agree to provide diagnosis, treatment, evaluation, and consultation with a patient. As we work to balance the privacy needs of the individual seeking substance abuse treatment, we also need to ensure that providers are able to access needed information in order to properly provide them with the treatment they need.

I want to make sure that, in an effort to improve coordination of care, we do not sacrifice the rights of individuals seeking needed treatment for their addiction. We have spent the past few months

working on addressing the opioid crisis and have learned from medical professionals that only a small fraction of Americans suffering from substance abuse seek treatment, in part out of fear that their medical records may be disclosed.

Current law allows for the disclosure of information under part 2 with regard to internal communications, medical emergencies, special court orders, in the event of a crime on the premises or against personnel on the premises, and entities covered under part 2, qualified service organization and business associate agreements.

Before our committee moves forward with the Overdose Prevention and Patient Safety Act, H.R. 3545, we need to make sure that the rights and privacy of patients seeking treatment are protected. I am open to considering changes to part 2, but these changes need to meet the current standard of protection that protect Americans seeking substance abuse treatment.

Mr. Chairman, I yield back the balance of my time.

[The prepared statement of Mr. Green follows:]

******** COMMITTEE INSERT ********

Mr. Burgess. The chair thanks the gentleman.

The chair recognizes the gentleman from Oregon, the chairman of the full committee, Mr. Walden, for 5 minutes.

The Chairman. Thank you very much, Mr. Chairman. Again, thank you for your leadership on this and so many other healthcare issues.

Today marks our fourth Health legislative hearing on solutions to address the opioid crisis, an epidemic that knows no geographic, political, or socioeconomic bounds. Throughout this process, part of this committee's approach has been to shift attitudes towards substance use disorder and treatment.

As I have stated before, substance use disorder is a medical illness, and we must treat it that way. Removing the stigma of addiction is one of the most important things we, as Members of Congress can do to respond to the national emergency, and it will dramatically change how we prevent and treat this complex issue.

During our work to develop policies to stem the tide of addiction and abuse, an extraordinary array of hospitals, physicians, patient advocates and substance use disorder treatment providers have approached this committee to clearly state that existing Federal confidentiality regulations, known as 42 CFR part 2, or part 2, are interfering with case management and care coordination to effectively treat substance use disorder.

The statute behind part 2 was enacted more than 20 years ago, 20 years before the Health Insurance Portability Act, or HIPAA, and 40 years prior to the use of electronic healthcare records. The intent behind part 2 was to protect patients seeking treatment from negative repercussions, such as incarceration or loss of employment, laudable goals.

And yet part 2 does not even apply to all substance abuse disorder patients, meaning some providers have full access to a patient's medical records and others don't. For the millions of patients suffering from substance use disorder who are treated by a provider not subject to part 2, their records are protected by HIPAA. Now, this begs the following question: Is HIPAA protective enough for those seeking substance use disorder treatment or not? If it is not, what can we do to better protect patient privacy and better coordinate substance use disorder treatment? Because, as currently written, the statute behind part 2 handcuffs providers, and it hurts patients.

Representatives Mullin and Representative Blumenauer have tackled this complex issue and written the Overdose Prevention and Patient Safety Act, which I believe strikes the right balance of maintaining and strengthening patient protections while allowing for the limited sharing of substance use disorder treatment records between healthcare providers, plans, and clearinghouses.

The legislation also includes strong penalties and discrimination prohibitions in statute to protect people seeking and receiving substance use disorder treatment. I have heard from providers in Oregon, from hospitals to healthcare centers to addiction specialists, who believe these changes are critical to their improving treatment of substance use disorder.

In fact, Mr. Chairman, I have a letter for the record from the Oregon Hospital Association commending our efforts I would like inserted, without objection.

Mr. Burgess. Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

The Chairman. So I understand this issue is a sensitive one. There have been a lot of discussions. There has been a lot of confusion, understandably so, about what this bill does or doesn't do, which is why we are having this extra hearing. Privacy law is complex, which is why we are having additional testimony in addition to what we heard in March.

So we are here to learn more about this issue, to listen to stakeholders on both sides of the argument. It is important we have a thoughtful discussion and get to the bottom of this.

The ranking member has made clear that he will evaluate bills based on two principles: One, whether the proposal improves access to treatment for opioid use disorders; and, two, whether the proposal helps to prevent people from getting addicted to opioids in the first place. I would argue that the Overdose Prevention and Patient Safety Act does both.

Treating patients' substance use disorder in isolation from their medical conditions, which predominated care in the 1970s, is not -- is not -- the standard of good medical practice today. This legislation will arm physicians with all the necessary information to provide the best care, ultimately improving access to treatment and preventing the unnecessary prescribing of substances that may cause patient harm.

With that, Mr. Chairman, I would turn the remainder of my time

to Mr. Mullin of Oklahoma, the leader on this issue for this committee.

[The prepared statement of The Chairman follows:]

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Mr. Mullin. Thank you, Mr. Chairman.

And thank you, Chairman Burgess, for allowing us to have this hearing today and for all the witnesses. Congressman Blumenauer and myself, we don't typically agree on a whole lot, but when we start talking about this, we do agree 100 percent on this issue.

This is about allowing the physicians to be able to see the complete record and be able to treat the patient as a whole, not just part. This is about destigmatizing what addictions really mean. It allows us to bring us back into the 21st century. When part 2 was first put up there, the medical field looked completely different than it does now. So, without part 2 alignment, we are going to continue to stigmatize patients with substance use disorder.

I urge all my colleagues today to take a look at how we can bring substance use disorder treatment and the rules and laws governing them into the 21st century. It is simple. We want to take care of the patients. The doctors want to take care of the patients. We need to move forward. This is something that has hit all of us personally.

With that, Mr. Chairman, I yield back.

[The prepared statement of Mr. Mullin follows:]

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The Chairman. And I yield back.

Mr. Burgess. The chair thanks the gentleman. The chair observes that there are a series of votes on the floor, so we are going to adjourn while we -- or recess while we attend to those votes on the floor. We will reconvene immediately after the last votes and hear from the ranking member of the subcommittee, Mr. Pallone, for his opening statement.

The committee stands in recess.

[Recess.]

Mr. Burgess. I will call the committee back to order. When the committee recessed for votes, we were in the process of hearing opening statements from members, and it is now in order to yield to the ranking member of the subcommittee, Mr. Pallone of New Jersey, 5 minutes for an opening statement, please.

Mr. Pallone. Thank you, Mr. Chairman.

Today's hearing provides a critical opportunity for committee members to better understand 42 CFR part 2 and the legislative proposal to roll back the heightened protections it provides.

As I noted at the subcommittee markup, we all agree that action must be taken to combat the opioid epidemic ravaging our country, but taking the wrong action because we are not spending the appropriate amount of time to understand the consequences of a proposal could have

serious consequences of making things worse. And that is why I requested a separate hearing that just focused on part 2 and any legislative proposal that would make changes to it. And, as you know, not only is this issue controversial, but it is complicated.

So I thank the chairman for having this hearing, because I think it will help members hear firsthand why the substance use disorder patient advocacy community is united in their opposition to rolling back the protections of part 2. This is the community that will bear the ultimate burden of this action, and, therefore, we should listen to their thoughts before making any changes that could potentially cause harm. And we will also hear more about why the substance use disorder provider community is split on this issue.

Mr. Chairman, you know we are in the midst of the worst opioid epidemic in our country's history. While I appreciate the bill's sponsors' intention to help build a better healthcare system for the patient community, I do have concerns with the proposal before us. Confronting the opioid crisis requires identifying strategies that promote more people entering and remaining in treatment for opioid use disorder. This is critically important because major challenges exist to getting people with substance use disorders to enter treatment. In fact, SAMHSA's National Survey on Drug Use and Health found that only about 4 million people out of approximately 21 million Americans in

need of substance use disorder treatment received it in 2016, and that is only 19 percent.

And I believe that any action that will potentially prevent people from seeking treatment for any substance use disorder, and particularly opioid use disorder, must be avoided. Unfortunately, the proposal before us I think risks doing just that, reducing the number of people willing to come forward and remain in treatment.

Part 2 generally requires patient consent to share their substance abuse disorder medical records. That is because individuals might not seek or remain in treatment if they are worried about the real negative consequences that seeking treatment can have on their lives. It can mean the loss of a job, a home, or a child. It also could mean discrimination by doctors and insurers or, worse, arrest, prosecution, and incarceration.

Disclosure of substance abuse disorder information has tangible consequences that are not the same as other medical conditions. You can't legally be fired for having cancer. You are not denied visitation to your child due to severe acne, and you are not incarcerated for having a heart attack.

But ensuring strong privacy protections is critical to maintaining people's trust in the healthcare system and willingness to obtain needed health services, and these protections are especially

important where very sensitive information is concerned.

So I think we are at a critical moment. At this moment, I believe we should heed the advice of the congressional conferees that negotiated the confidentiality statute that created part 2, and I am quoting. It said: The conferees wish to stress their conviction that the strictest adherence to confidentiality of substance use disorder patient records is absolutely essential to the success of all drug abuse prevention programs. Every patient and former patient must be assured that his or her right to privacy will be protected. Without that assurance, fear of public disclosure of drug abuse or of records that will attach for life will discourage thousands from seeking the treatment they must have if this tragic national problem is to be overcome.

Once again, we face a tragic national drug abuse problem, the scale of which our country has never seen. And I believe maintaining the heightened protections of part 2 remain vital to ensuring all individuals with substance abuse disorder can seek treatment for their substance abuse disorder with confidence that their right to privacy will be protected, and to do otherwise at this time I just think is too great a risk.

I yield the rest of my time to the gentlewoman from California, Ms. Matsui.

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[The prepared statement of Mr. Pallone follows:]

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Ms. Matsui. Thank you, Ranking Member Pallone, and thank you, Mr. Chairman, for holding this hearing today. This is a very important complex issue relating to the opioid epidemic. I feel strongly that we should take action in this space. Patients that are currently receiving treatment may not be getting the best care if their provider does not have all the information necessary.

However, many challenges remain, only some of which might be solved by this bill. Providers still don't always have electronic health records, and even when they do, information is not always shared across providers. We cannot fully coordinate care if substance abuse is not a part of your medical history.

However, we are walking a fine line. As much as we need to reduce stigma and move toward integrated care, we still face technological, medical, and social barriers. Most of all, we do not want to unintentionally harm patients who may still be discriminated against for their addiction.

I look forward to the discussion today, and I thank the witnesses for their testimony.

Thank you, and I yield back.

[The prepared statement of Ms. Matsui follows:]

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Mr. Burgess. And the gentleman yields back. The chair thanks the gentleman.

This concludes the member opening statements. The chair would like to remind members, pursuant to committee rules, all members' opening statements will be made part of the record.

Testifying for our first panel is Congressman Earl Blumenauer.

Thank you, Mr. Blumenauer, for being with us today and taking your time to testify before the subcommittee. We look forward to what you have to share with us.

Just as a housekeeping detail, as is the general custom with a Member testifying, we will not do questions, but we will go directly to our second panel of witnesses.

Congressman Blumenauer, you are now recognized, 5 minutes, to summarize your opening statement.

STATEMENT OF THE HON. EARL BLUMENAUER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON

Mr. Blumenauer. Thank you, Mr. Chairman, for your courtesy, and I appreciate the opportunity to share some observations with you to be able to discuss how better to provide high-quality coordinated care for patients with substance use disorders.

And I heard my two colleagues here, and I agree, but we are looking here -- I will put it slightly different. We have an antiquated law that prevents lifesaving medical care for patients in recovery for substance use disorders. Originally designed to protect the privacy of individuals in addiction treatment, this decades-old barrier now creates an impediment to the implementation of integrated care.

Drug Abuse Prevention, Treatment, and Rehabilitation Act of 1972 currently governs how doctors and healthcare professionals share alcohol or substance use disorder records. Under this law, which predates HIPAA of 1996, patient medical records from addiction treatment facilities are segregated from the patient's medical records. And this can create a life-threatening firewall that prevents medical doctors from knowing their patients' full medical history, which could include treatment for substance use disorders.

The rules that govern this firewall, known as 42 CFR part 2, or simply part 2, are more restrictive than HIPAA. It supersedes HIPAA and can only be breached in an emergency or with express written consent of the patient. This consent can often be impossible or difficult to maintain, and in those instances, the care itself cannot be fully integrated. Failure to modernize part 2 has weakened our Nation's ability to respond to the ongoing opioid crisis that is contributing to a record number of drug overdose deaths in 2017 and are continuing.

Our Nation's healthcare delivery system has changed and innovated over the last 45 years. As providers shift towards new coordinated models of care, they must rely on shared medical information to improve patient health.

Regulations in part 2 restrict the providers' ability to access critical substance treatment information, which can result in poor and in some cases tragic outcomes. And I believe the subcommittee has heard some really jarring testimony to this effect. Doctors can't treat a whole patient with half a medical record. And patients have a right to the best medical care available. Along with Representative Mullin, we have been pleased to author this bipartisan Overdose Prevention Act to prevent tragedies such as the committee has heard.

The legislation would treat medical records generated at a substance use treatment facility that relate to treatment, payment,

or healthcare operations in exactly the same manner as all other medical records, removing the stigma that has for so long segregated those records from the rest of the healthcare system.

At the current time, persons with substance use disorders are the only subset of the healthcare patients whose records are treated differently and, as a result, may not receive the coordinated care they need.

Now, there is stigma associated with mental health and HIV/AIDS, but both mental health and HIV/AIDS fall under the protections of the HIPAA privacy law. Care is improving for both of those populations, thanks to increased access to public health data and open lines of communication that reduce unnecessary discrimination.

For Americans who are in recovery, our legislation maintains and strengthens part 2 protections, to prevent disclosure of information. For example, it is currently illegal to share individuals' substance treatment record for an employer, law enforcement, or landlord. That wouldn't change under this legislation. Indeed, we would strengthen the penalties for unauthorized disclosure to make it more secure. As the healthcare system moves forward, more robust, integrated care models, every member of a patient's treatment team needs to understand the patient's full medical history, including substance abuse disorder. Current part 2 regulations stand as a hindrance to the whole

person care, and I think they must be changed to ensure all patients, regardless of diagnosis, have access to safe, effective, high-quality treatment and care.

I deeply appreciate the opportunity to share some observations with you and look forward to your discussions in this area to be able to give people the big picture. Thank you very much.

[The prepared statement of Mr. Blumenauer follows:]

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Mr. Burgess. Mr. Blumenauer, thank you for providing your testimony to the subcommittee today. It is a very valuable part of our insight into solving this problem.

The Chairman. Mr. Chairman, before my colleague from Oregon departs the table --

Mr. Burgess. The gentleman is recognized.

The Chairman. -- I would point out that, in 1972, he was winning his first election to the statehouse at the age of either 23 or 24, depending upon when this was written into law. So not that it has been a long time since 1972, but he has had a very distinguished career ever since. On the city council, he and my father served -- my father and he served together in the State legislature. Yeah, he does go back that far. And then here in the Congress. So we appreciate him being here and sharing this.

Mr. Blumenauer. And his father was the real legislator.

The Chairman. Mr. Chairman, is this where I move to table the bill?

Mr. Green. Does the chairman yield? Mr. Chairman, I was also elected in 1972. Are you telling me we are old?

The Chairman. I would never -- no. I am saying the law that was started in 1972 is old.

Mr. Burgess. The chair thanks the historical perspective that

all have provided today.

Mr. Blumenauer, again, thank you for sharing with us.

And we will transition into our second panel. And as we do that, I want to thank all of our witnesses for being here today, and join us at the witness table. Each witness is going to have the opportunity to give an opening statement, followed by questions from members.

Do we have our name placards at the ready?

So, as Zach is placing the names, today we are going to hear from Mr. Dustin McKee, director of policy, the National Alliance on Mental Illness, from Ohio; Ms. Patty McCarthy Metcalf, executive director, Faces and Voices of Recovery; Mr. Jeremiah Gardner, manager of public affairs and advocacy, Hazelden Betty Ford Foundation; Dr. Westley Clark, the dean's executive professor, Public Health Program, Santa Clara University; and Mr. Gerald DeLoss, officer, Greensfelder, Hemker and Gale, Public Corporation.

We appreciate each of you being here today. And, Mr. McKee, you are now recognized for 5 minutes for an opening statement, please.

STATEMENTS OF DUSTIN MCKEE, DIRECTOR OF POLICY, THE NATIONAL ALLIANCE ON MENTAL ILLNESS OF OHIO; PATTY MCCARTHY METCALF, EXECUTIVE DIRECTOR, FACES AND VOICES OF RECOVERY; JEREMIAH GARDNER, MANAGER OF PUBLIC AFFAIRS AND ADVOCACY, HAZELDEN BETTY FORD FOUNDATION; H. WESTLEY CLARK, M.D., J.D., M.P.H., THE DEAN'S EXECUTIVE PROFESSOR, PUBLIC HEALTH PROGRAM, SANTA CLARA UNIVERSITY; AND GERALD (JUD) E. DELOSS, OFFICER, GREENSFELDER, HEMKER AND GALE, P.C.

STATEMENT OF DUSTIN MCKEE

Mr. McKee. Thank you, Mr. Chairman.

Chairman Burgess, Vice Chair Guthrie, Ranking Member Green, and members of the Energy and Commerce Subcommittee on Health, thanks for this opportunity to testify before you today on H.R. 3545, the Overdose Prevention and Safety Act. As you all well know, our Nation is in the midst of a public health crisis.

Between 2014 and 2016, in my home State of Ohio, 10,383 people died from an opiate-related overdose. One of those people that died during that time was my big brother, Brandon J. McKee. He was 36. He left behind three sons, 4, 11, and 16. Mr. Chairman, Brandon's death was preventable. However, the antiquated provisions of 42 CFR part

prevented his medical professionals that were prescribing him high doses of opiate-based pain medications with multiple refills from knowing that they were treating a high-risk patient with an ongoing history of substance abuse treatment and relapse.

But before I start describing the events leading to his death, I want to tell you a little bit about Brandon. Brandon struggled for most of his life with addiction disorder, but in spite of it, he found success early. My big brother was the best salesman you will ever meet. I mean, this guy could sell a double bacon cheeseburger to a vegan. He was a talented salesman that made six figures by the time he was 20 years old selling cars in Mansfield, Ohio, as a sales manager.

But despite two courses of residential treatment and periodic outpatient treatment for substance use disorder, his substance use led to several job losses, multiple DUIs, lots of family strife, and an eventual divorce. After that divorce, he moved into my mom's basement. She was kind enough to let him be there to try and get sober.

One night, he decided to go out and he got into a terrible car crash that crushed a few vertebrae in his spine. He was transferred up to Cleveland Metro Hospital. The orthopedist had no way of knowing he was an addict. So, after the surgery, he was prescribed high doses of opiate-based pain medication with multiple refills. Four months later, interestingly enough, he broke his back again while riding his

bike and getting into a wreck. Again, he went to that same surgeon, and, again, he was prescribed high doses of opiate-based painkillers with multiple refills. He didn't sign a 42 CFR waiver. He was an addict. He was about ready to get the holy grail. Those drugs made him feel perfect.

We didn't even know that he was on narcotics until -- well, I was the last one to speak with him 3 days before his death. He had burned all his bridges because of the secrets and lies associated with his addiction disorder. He called me that day and admitted that it was more than just the alcohol and that he was taking pills. And I said I was proud of him for telling me about it. Ironically, his phone battery was drained that day, and his phone cut out before the conversation was over. His last words to me were, "I am going to go to that NA meeting tonight, I promise, brother." Three days later, he died of a heroin overdose. He was found alone in his apartment curled up on the floor in the fetal position. It was May 10, 2014.

Mr. Chairman, Brandon's story demonstrates that 42 CFR part 2 is a significant barrier to integrating care for behavioral health, medical/surgical care, and aftercare. It is also a major patient safety issue. We at the National Alliance on Mental Illness know that siloed treatment for mental illness and addiction is ineffective, leads to negative outcomes. This is common sense.

I would further emphasize that H.R. 3545 takes a very narrow targeted approach that simply aligns 42 CFR part 2 with HIPAA for the purposes of sharing information only for treatment, payment, and healthcare operations. There is no risk that the records will be shared with outside parties, like landlords, employers, law enforcement, or exposing folks to civil litigation.

These are commonsense policy changes. You can make these changes. The lives of your constituents may just depend on it.

Thank you for this opportunity to testify before you today. I would be happy to answer any questions.

[The prepared statement of Mr. McKee follows:]

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Mr. Burgess. Mr. McKee, thank you for your testimony.

Ms. Metcalf, you are recognized for 5 minutes, please.

STATEMENT OF PATTY MCCARTHY METCALF

Ms. Metcalf. Good afternoon. And, first, I would like to thank the committee for hosting this important hearing and for inviting me to testify. My written and oral testimony are the result of my experience as a person in substance use disorder recovery, as well as my professional experience as the executive director of Faces and Voices of Recovery.

I am a woman in long-term recovery from alcohol and drug addiction. For me, that means I haven't used alcohol or drugs in over 28 years. And that recovery has allowed me to give back to my community, earn college degrees, own a home, raise a family, pay taxes, establish a career, and become a leading advocate for the recovery community.

As an organized voice protecting the rights of individuals with substance use disorders, Faces and Voices of Recovery is adamantly opposed to dismantling of our critically important 42 CFR part 2 confidentiality protections. We do not want our highly sensitive personal information shared for the purposes of treatment, payment,

healthcare operations, or for any other purpose beyond the current rule without our express written consent.

We agree with the Congress who enacted part 2 in the 1970s that weakening privacy regulations will discourage individuals who need treatment from seeking it. The dismantling of part 2 is the antithesis of the principle of patient-centered, integrated care and is largely being pursued by coalitions and entities who hold their own business interests ahead of the rights of the interests of our community. These protections are as critical now as they were 40 years ago and must be maintained to ensure that individuals and families will seek help.

We believe that the interaction between a treatment provider and the client, when discussing specific consents and disclosures, strengthens the therapeutic relationship and builds trust. Patients feel secure enough to know where their personal health information is going and for what purpose. Most often, the treatment provider encourages their clients to provide a written consent, to share information with their primary care physician, but if the client is reluctant to do so for whatever reason, they have an opportunity to weigh the benefits and discuss the options.

We wouldn't be here today discussing part 2 if it weren't for the fact that we are in the midst of an opioid epidemic. But I want to remind you that the Federal confidentiality regulations are intended

to protect the privacy for all individuals with all substance use conditions, not just those with opioid use disorders.

There are an estimated 16 million people like me in the United States that have an alcohol use disorder. And research has repeatedly shown that people with alcohol use disorders experience stigmatization by the public as well as from health professionals more severely than people with mental disorders. This perceived stigma is shown to reduce the probability of using healthcare services and thereby contributes to a decreased likelihood of seeking treatment.

Research also indicates that worries about privacy keep people from seeking treatment. Making these changes to minimize our privacy protections will have long-lasting effects for a wide range of individuals and family members. The potential for negative consequences of stigma and discrimination with regard to employment and education is real for millions of Americans, even after years of sustained recovery from alcohol and drug addiction. And unlike most other medical illnesses, substance use disorders often have criminal and civil, legal consequences, and patients are vulnerable to arrest, prosecution, and incarceration.

Patients may be hesitant to reveal they have been discriminated against, because they would have to disclose the use of illegal drugs as well as the activities that are associated with the use of illegal

drugs. The vast majority of persons who will have this happen to them will lack the resources to determine who used their information in an improper way. Even if they did know this, in most cases, they would not take action for the very fact that trying to assert their rights would acknowledge drug use and addiction in a way that would open them up to prosecution and discrimination. Part 2 provides safeguards for patients against potentially disastrous results of unauthorized disclosure.

In conclusion, beyond the significant harm that eliminating part 2 would do to our communities, it is entirely unnecessary. There is far too much at stake here for those of us depending on these protections in order that we may heal and realize our full potential as productive citizens of this great Nation. Many of us have made it clear that we would not have gone to substance use disorder treatment or accepted services if we thought our information would be shared with other entities without our permission or knowledge. We would not have put our careers, reputations, our families at risk of stigma and discrimination if we were not assured that our information about our substance use disorder was safe and would only be shared with our consent. As a person in long-term recovery, a parent, and on behalf of the recovery community, I look forward to working with members of the committee to protect patient privacy.

And thank you for the opportunity to testify and address such an important issue to our community.

[The prepared statement of Ms. Metcalf follows:]

******** INSERT 1-3 ********

Mr. Burgess. Thank you, Ms. Metcalf.

Mr. Gardner, you are recognized for 5 minutes, please.

STATEMENT OF JEREMIAH GARDNER

Mr. Gardner. Mr. Chairman, thank you for inviting me. I am grateful to you and the subcommittee members for your leadership in addressing opioids and addiction and for this opportunity to testify in support of H.R. 3545.

My name is Jeremiah Gardner, and I am a person in long-term recovery from substance use disorder. I am also a recovery advocate with a master's degree in addiction studies and a counseling license. In addition, I work as a communications professional for the Hazelden Betty Ford Foundation, a nonprofit that has been advocating for patients and helping them overcome addiction for decades.

I believe all of us here today can agree about the need for more coordinated and integrated care, less discrimination against those with substance use disorder, and appropriate patient privacy. We all want to help patients, not harm them. H.R. 3545 is not a question of privacy versus no privacy or coordination versus no coordination or discrimination versus no discrimination, providers versus patients. The very specific question, as the chairman noted, is, does HIPAA

provide sufficient enough privacy protection to warrant removing the part 2 barriers that sometimes get in the way of more efficient, coordinated care.

And as you weigh that choice, I would like to tell you about my mom, who is another illustration of why this topic is so important. At age 59, my mother misused fentanyl patches, Vicodin, and anxiety medications, and died just a couple of rooms away from her husband and 13-year-old grandson.

She had started taking prescribed opioids 20-some years earlier for pain. Eventually, she was on 400 milligrams of morphine a day, which over time led to other ailments, deteriorating mental health, and additional medications, not to mention more doctors. She had lots of them, and lots of medications.

But before her long journey with opioids began, she was treated for alcohol problems at a part 2 facility. It was a significant fact in her health history that, as far as I can tell, escaped the attention of her later doctors and failed to inform her healthcare moving forward.

Two decades later, at the end, my mom suffered from a complex combination of opioid use disorder, chronic pain, acute pain due to knee surgery, depression, anxiety, arthritis, type 2 diabetes, and other physical conditions. She also had an assortment of social stresses and, because she relied so much on pills for so long, a deficit

of healthy coping mechanisms. Her pain was, indeed, profound, manifesting itself like addiction does, physically, mentally, emotionally, socially and spiritually.

What my mom needed but never got was a good year or more of integrated, coordinated care, and checkups surrounded by support. She needed her multiple care providers to have the full picture of her health and to work together. Instead, they kept prescribing deadly amounts and combinations of drugs to somebody with a substance use disorder. My mom got subpar care.

Could she have done more to actively coordinate care herself? Yes. But as a professional in the field and someone with lived experience, I can tell you that that is a tall order for someone with a severe substance use disorder. Maybe she was too embarrassed or ashamed to acknowledge her condition because of the public stigma. Maybe she didn't understand she was at greater risk, or maybe she did and was not inclined to volunteer information that might prevent her from getting pills for her pain or her anxiety.

She eventually came to know opioids as a relentless monkey on her back, but she also saw them as a solution. And that drive to continue using despite problems reflects the very nature of addiction. My mom needed help recognizing that her constellation of issues tied together, and that substance use disorder was in many ways at the center of it.

My point in sharing is simply that the health of people like my mom can be very complex. Coordinated care is critical and too often absent, and timely relevant information sharing is important.

This bill isn't just about IT or workflows or convenience or efficiency or stigma or cost. It is about knocking down any barriers we can to help ensure optimal care. It is about taking the next step toward parity and bringing the full weight of healthcare to bear against this public health problem. Most of all, it is about people, real people with families like my mom.

There is some fear this bill will discourage help seeking. I certainly don't speak for all patients or family members, but I can tell you privacy laws were not a factor in my own help seeking or my mom's contemplations. And the topic, frankly, is rarely broached by the thousands who call the Hazelden Betty Ford Foundation for help each year. Most want to know, can you help, and how can I pay for this?

I really believe this bill addresses those priorities that patients and their families care about most. I also believe HIPAA is a sufficient and enforceable privacy standard, that discrimination can and must be prosecuted vigorously, and that this is an essential piece of the Federal opioid response and the paradigm shift that began with the 2008 parity law.

Thank you for the opportunity to share. I look forward to

answering your questions.

[The prepared statement of Mr. Gardner follows:]

******** INSERT 1-4 ********

Mr. Burgess. Thank you, Mr. Gardner.

Dr. Clark, you are recognized for 5 minutes, please.

STATEMENT OF H. WESTLEY CLARK, M.D., J.D., M.P.H.

Dr. Clark. Thank you, Mr. Chairman, Mr. Green, and members who are assembled. Thank you for the opportunity to present to you here today.

I am here as a physician, addiction medicine specialist, and as a college professor. I am here to advocate for maintaining the integrity of 42 U.S.C. 290dd-2 and for keeping those Federal regulations that protect individuals with substance use disorders. Do not discourage them from seeking treatment by stripping away their current right to consent to the release of their personal substance use disorder histories.

There are two contemporary phenomenon that are relevant here: one, the Facebook Cambridge Analytica issue; and, two, the NIH All of Us longitudinal research project. In the case of the Facebook Cambridge Analytica issue, it was clear that the general discourse about the misuse of information, that privacy and confidentiality were important to people and the disclosure of their private information without their consent was a violation. That the information was

subsequently used for predictive analytics for the purpose of influencing those whose information had been compromised shows the potential for abuse. This was not a case of data security, but a case of breach of confidentiality and apparent invasion of privacy.

Alternatively, the NIH study will include all data available in the participants' electronic health records, including demographics, visits, diagnosis, procedures, medications and laboratory visits. Pertinent information can include data about mental health, substance use, or HIV status.

What is interesting about the NIH All of Us study and relevant to this hearing is that participants will be asked to consent to release information from their electronic health records. The All of Us study invokes the idea of the comprehensive health record heralded by some EHR vendors, who seek a new generation of electronic information about people, information that includes all sorts of medical and nonmedical information. Thus, the medical record becomes a comprehensive dossier on the individual.

The actual benefit to a patient of integrating all that is known about an individual using the health record as the portal has yet to be determined. Privacy, confidentiality, and consent are important to Americans. If the two vignettes that I have used to introduce my testimony can be understood in the context of the current discussion,

then you, as Members of Congress, will understand the importance of maintaining the projections of 42 U.S.C. 290dd-2 and 42 CFR part 2 to a population that is more vulnerable than those on Facebook or those who agree to participate in the All of Us study.

While the issue of opioid misuse is of major importance, we should keep in mind that 42 CFR part 2 does not just apply to opioids. The National Survey on Drug Use and Health reveals that 65 million Americans admit to binge drinking in the past month and 24 million Americans admit to being past month users of marijuana.

The critical question today is, how do we get the 28.6 million Americans who are current illegal drug users and the 65 million Americans who are binge drinkers to discuss their substance use with the medical community? We won't do it by compromising their privacy.

It is also argued that substance use is like the flu, diabetes, hypertension, or HIV, and, therefore, should be treated like those conditions with regard to disclosure. The reality is that most substances of misuse are illegal and that disclosure of such information can give rise to harm to the individual affected. These harms include loss of employment, loss of housing, loss of child custody, the loss of benefits, stigma and discrimination, the loss of privacy, shame, and the loss of economy.

The case is often made that healthcare delivery systems need to

know about the substance use history of a patient. You don't hear why providers can't simply ask patients themselves about their substance use histories. You hear it is too confusing clinicians know about 42 CFR part 2 and how to apply the rule. Yet these same clinicians and healthcare systems spend quite a bit of time learning about and executing reimbursement rules, administrative rules, quality standard rules, and all the rules that are necessary to get paid for services delivered to the very people whose agency and dignity are now deemed too inconvenient to respect.

You may also hear that people lie about their substance use, implying that they cannot be trusted. However, since behavioral care is the dominant form of substance use treatment, trust is the cornerstone with behavioral treatment. We should be promoting a patient-provider cooperative relationship instead of encouraging an adversarial one.

The healthcare operations exception found in HIPAA is a loophole in confidentiality that is so large you can drive a Mack Truck through. Neither provider not regulators will be able to protect those with substance use disorders. The only choice left to those who are vulnerable is not to seek treatment. Remember, 90 percent of those who currently need treatment do not seek treatment. We should be focused on reducing the ratio of those who need treatment versus those

who seek treatment from nine to one, to one to nine.

Therefore, I ask you, please do not weaken 42 U.S.C. 290dd-2, and as a result, I ask you to look closely at H.R. 3545. It is not the panacea that it is being marketed as being. Thank you.

[The prepared statement of Dr. Clark follows:]

******** INSERT 1-5 ********

Mr. Burgess. Dr. Clark, thank you for your testimony.

Mr. DeLoss, you are recognized for 5 minutes please.

STATEMENT OF GERALD (JUD) E. DELOSS

Mr. DeLoss. Thank you. My name is Jud DeLoss. I am an attorney with Greensfelder, Hemker and Gale in Chicago, Illinois, and I practice in behavioral health law as well as health information privacy and confidentiality.

I represent several behavior healthcare providers that are governed by 42 CFR part 2 as well as others that are impacted by those provisions and overly restrictive provisions, including the county of Lake County in Illinois, Nicasa, North Central Behavior Health Systems, Stepping Stones Treatment Center, and TASC. Each of these are large and small providers that have had to come to bear and deal with these provisions and these restrictions.

I am here today on behalf of Netsmart Technologies, a technology partner with the behavioral healthcare space, and I am here today to discuss the protections that are provided under HIPAA as well as under 42 CFR part 2 and the legislation that we are discussing, as well as those protections that would be not only retained but enhanced by H.R. 3545.

At the outset, I wanted to describe those limitations that would remain in place because of H.R. 3545, as amended. As mentioned earlier, the only change that the bill would provide in terms of disclosures without consent would be with respect to treatment, payment, and healthcare operations. We are not talking about disclosures for legal proceedings. We are not talking about disclosures to law enforcement. We are not talking about disclosures to employers, landlords, marketers, et cetera. We are talking about those limited purposes that are the primary types of opportunities and activities that all sorts of healthcare providers engage in.

In addition, and more specifically to address some of the concerns that were raised about operations and the extent and scope of exchanges of information for healthcare operations under HIPAA, the disclosures allowed under the bill would only be allowed to other covered entities.

Covered entities is a HIPAA-defined term. It includes only healthcare providers, health plans, and healthcare clearinghouses, those entities that assist in the reimbursement process. Only those three entities would be allowed to receive part 2 information under the bill. It would not be fair to say that this information could be shared with third parties. It would not be fair to say that it could even be shared with business associates, strictly reading the terms of the bill. So we would not open up the exchange of information to

third parties that have no business. These are parties that need this information in order to carry out payment, treatment, and healthcare operations.

The bill itself provides substantial protections, in terms of the disclosures for civil, criminal, and administrative proceedings. The bill actually enhances those protections that 42 CFR part 2 previously had in place. So there are increased and heightened types of protections that are available.

I did in my written comments set forth a lengthy review of the protections that are available under HIPAA, those in terms of the protections, in terms of legal proceedings, employers, also the impact of the Americans with Disabilities Act if any of this information should happen to get into the wrong hands. SUD is a disability under the ADA and is protected as such, as set forth in my written comments. Landlords and housing agencies would also be governed by HIPAA as well as the ADA. The law enforcement and legal proceedings exceptions under HIPAA are very narrow and very stringently enforced, primarily requiring a court order or patient consent in order for the information to be shared for those purposes.

One of the areas that I did want to address is the inability under the current part 2 regulations to allow for a patient to make a choice in terms of sharing their information for treatment, payment, or

healthcare operations, as defined under this law as well as HIPAA.

In addition, I think it is important to note that if a part 2 program does not want to share information, this bill and HIPAA, more importantly, would not mandate a disclosure without consent. The SUD treatment program has the opportunity to impose higher or more stringent protections against disclosure, not those simply set forth under HIPAA. So there is a choice not only for patients but also for programs or others that might be concerned about disclosure.

To summarize the impact of the bill, a disclosure for treatment, payment, or healthcare operations can only be made to a covered entity. That recipient -- the covered entity, a healthcare provider, a health plan, or a healthcare clearinghouse -- would then be bound by these regulations or this law not to disclose that information to anyone other than another covered entity down the line.

So, in conclusion, I wanted to correct some of the misunderstandings with respect to HIPAA, misunderstandings with respect to the scope and impact of this law, and point out that HIPAA itself over the history of its enforcement has resulted in millions of dollars in fines and penalties, a comprehensive enforcement mechanism, where 42 CFR part 2 has not. Thank you for your time.

[The prepared statement of Mr. DeLoss follows:]

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

******** INSERT 1-6 ********

Mr. Burgess. Thank you, Mr. DeLoss. And I want to thank all of our witnesses for testifying before us today.

And we are going to move into the question portion of the hearing. I am going to begin that portion by yielding my time to the gentleman from Oklahoma, Mr. Mullin, 5 minutes for your questions.

Mr. Mullin. Thank you, Mr. Chairman.

And thank you for all of our witnesses that are here today.

Since I only have 5 minutes, I am going to get right into it.

Dr. Clark, are all substance disorder providers subject to 42 CFR part 2?

Dr. Clark. If they are federally assisted.

Mr. Mullin. The answer is, are they all subject to it?

Dr. Clark. Only if they are federally assisted.

Mr. Mullin. So the answer to that is no. And they are not all Federal assistance, because the VA doesn't fall underneath part 2. The VA doesn't fall underneath it, and they are Federal assistance.

Dr. Clark. The VA has its own 38 CFR.

Mr. Mullin. The question was, do all of them fall underneath 42 CFR?

Dr. Clark. No.

Mr. Mullin. So is there evidence that patients that don't fall underneath it, has that been abused?

Dr. Clark. Well, you invoked the VA. I used to work for the VA, spent 14 years --

Mr. Mullin. Sir, I said, is there evidence, is there evidence that people that do not fall underneath 42 CFR part 2, is there evidence that those, that their medical records are being abused and they are being discriminated against?

Dr. Clark. I couldn't say that there is.

Mr. Mullin. Because it is no.

Part 2, how many times has it been tried, violators? People that violated part 2, how many times has it been tried?

Dr. Clark. It is not a heavily litigated area.

Mr. Mullin. Heavily. It has never been. It has never been.

Dr. Clark. It has been litigated, sir.

Mr. Mullin. No, it is exactly zero. I have the information right here. And I know that you can give your opinion, but we are dealing with facts here.

Dr. Clark. Okay, I am a lawyer also, sir. And so from 1970 --

Mr. Mullin. No, no, hang on, it is my time. You said a lot in your 5 minutes. I am just pointing out holes in it.

Now, underneath HIPAA, how many times has it been tried? 173,426 times since 2003. Because part 2 is unenforceable. They can't comply with it. It is only a $50 penalty.

You start talking about discrimination. In your testimony, you said that the harms to which a person who admits to substance use may suffer includes the loss of employment, the loss of housing, the loss of child custody, the loss of benefits, stigma, discrimination, the loss of privacy, and the loss of anonymity.

How would that actually work? How would you do this legally underneath the system that is there? Is that just an assumption that you are making? Because there is no legal way to actually do that. There are laws already that protect the individual from that. Is that not true?

Dr. Clark. No, that is not true for --

Mr. Mullin. Oh, there isn't? Well, you are an attorney, so explain that to me then.

Dr. Clark. Okay. If I am an active substance user, the ADA does not protect me. The Americans with Disabilities Act does not protect an active substance user who is using illegal substances.

Mr. Mullin. So there are not any laws that protect people from being discriminated against? Because as a person that also has several property companies, I can't use that information to deny someone from housing. As an employer, I can't use that to deny someone for employment, because it would be discriminating. So you are making an assumption here that is actually not accurate.

Now, you also said in your testimony that you are comparing my bill to the Cambridge Analytica/Facebook issue. How is adding antidiscrimination language and extra protection for patient information comparable to the Facebook data scrubbing?

RPTR ALLDRIDGE

EDTR SECKMAN

[2:30 p.m.]

Dr. Clark. The issue is data scrubbing. Just as you said, the healthcare --

Mr. Mullin. I am not talking about data scrubbing here.

Dr. Clark. We are talking about data scrubbing.

Mr. Mullin. Who is scrubbing it?

Dr. Clark. When you are talking about electronic health records, you are talking about predictive analytics, and you are talking about data scrubbing.

Mr. Mullin. Yeah. But we already show that the only people this covers is essentially Medicare and Medicaid. And when we get into the situation that private payers in VA, that they are not being discriminated against, why is this such a big issue now?

Because you are making a lot of assumptions. And, sir, I know that you are able to make the assumptions. But we are also dealing with people's lives.

Is there anybody in here that doesn't be touched by -- this has touched me three different times, and I take it very personal. And when people come here and they want to give their opinion, and it is

not based on facts, it really bothers me. I am sure you are a very smart individual. Sir, I am sure you are a very smart individual, but you are coming in here, and you are just giving your opinion.

Dr. Clark. Well, you wanted to know about, for instance, unemployment. The ADA does not apply to active substance users. That is a fact. That is not an opinion. So I can't help you with that.

And, in fact, there are rules historically for housing. HUD used to have, and still does have, rules that allow you to discriminate against people who --

Mr. Mullin. What are those rules? What are those rules?

And, besides, by the way, you just mentioned another Federal agency. And this is about Federal protection for those on Medicare and Medicaid. We are talking about the private sector, because that is what you are making comparisons to.

And, sir, I am very serious about trying to protect people's lives here. And I know you are too. But we got to make sure that we are dealing on the same page. And while I respect your ability to give your opinion, I completely disrespect your testimony because it is based on opinion, not facts.

With that, I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentleman, the ranking member of the subcommittee, 5 minutes for questions, please.

Mr. Green. Thank you, Mr. Chairman.

I want to thank our witnesses for being here, because this is something that is really important because it -- we have chemical addictions so rampant that we are changing law that provides more protection for someone chemically instead of just a mental or anything else.

And, Dr. Clark, you have read the language in the bill. Is there any way that we could -- as a lawyer, you could suggest other language than what is in the bill that would have some protection there that we still do? Because a number of us have concern about this legislation. But I also know, under HIPAA, this is much more stronger than anything HIPAA has, the bill does.

Is there anything you would suggest that would feel more comfortable to both you but also to Ms. Metcalf? Because I understand, we all have relatives who really don't want to tell us what their issues are. And they have some right to privacy no matter what they have.

Dr. Clark. Well, as -- the first thing, as a physician, if your patient doesn't trust you, they won't disclose information to you. That is what gets lost in this.

We know that people with mild to moderate conditions that lead

to severe conditions don't talk about their substance use. So, if you want to save lives, you do it upstream. You don't wait until the problem is so severe that it is actually quite transparent to everybody in the room. And that is what actually happens. People hide their substance use, and there is no record of it.

All the stories that you hear, how horrible they are and how tragic they are, the stories are that the people do not feel comfortable disclosing what is going on. So 90 percent of the people who meet criteria for an SUD don't discuss that with the healthcare delivery system.

Now, the question is, is there any way to address this? The healthcare operations component of HIPAA, as I said in my 5 minutes, it is so broad that it gives rise to -- when you start explaining that to people, if you can explain it to them clearly, they will understand that they really have no privacy, and so they will keep their mouths shut.

And by the time you are aware that their problems are so severe that they need intervention, it will become transparent. We will hear -- your committee has dealt with physicians who have misused prescribing. We now know we have enough data of using prescription drug monitoring programs and other strategies that we can track what is happening with patients. So it won't be those people for whom

prescriptions are written, because now we can track those. We can enhance electronic health records.

There are models being proposed. The gentleman to my left, Mr. DeLoss, talked about working with the her community. I also work -- when I was with SAMHSA, worked with the her community. We had developed bridges to allow for patient consent, but the her community was not interested because there was not enough money in it for them. They had an opportunity earlier in this whole discussion when the HITECH Act was passed, they just were not interested.

I met with the major providers. They were not interested. It was -- this was small potatoes as far as they are concerned. Get rid of healthcare operations, and you have got a different bill that at least will allow people to address --

Mr. Green. Well, thank you.

And, Ms. Metcalf, I understand from where you are coming from. But we still have this issue that Mr. McKee said that, even as a family member, he wasn't getting information from his brother. And that happens whereas I don't know if HIPAA could be a change. The only thing I could say, as a lawyer, is that a family member gets a guardianship so you take over that oversight. And guardianships are tougher, because it is harder to get. But as a family, if you -- that is the only legal thing.

Mr. DeLoss, do you have any other options that a family member could use?

Mr. DeLoss. In order to share the information, correct. The current bill would not allow that direct sharing. It would allow for the sharing only to a covered entity.

As far as an alternative to share that information in that precise situation, there could be an anonymized disclosure. Part 2 programs -- in order to avoid some of the implications of part 2 that are overly restrictive and engage in a process to warn others. There is no duty to warn exception under part 2. So, if there is an issue where someone should threaten to kill someone, they cannot inform police or anyone else under part 2.

So what part 2 programs have done is to anonymize that disclosure, disclose it in such a way that does not indicate where it came from or who it is about specifically with respect to their SUD diagnosis.

So these are workarounds that SUD programs governed by part 2 must undertake in order to avoid these overly restrictive requirements.

Mr. Green. Thank you, Mr. Chairman. I know I am out of time.

Mr. Burgess. The gentleman yields back. The chair thanks the gentleman.

The chair recognizes the gentleman from Oregon, the chairman of the full committee, Mr. Walden.

The Chairman. Thank you, Mr. Chairman. And thanks to our panelists for being here as we work on this very difficult issue.

I have heard from my hospitals in Oregon who are very supportive of what we are trying to do here. They say this regulation makes it very difficult or prevents the sharing of patient information necessary to deliver effective and coordinated care. This conflict forces hospitals and health systems now to go to extraordinary lengths to deliver needed care.

In our panel with the survivors, many of whom lost children, this was an issue they raised. The lack of ability to know what is going on in their kids' lives. We have heard it from others about substance use disorder treatment. I know these are separate issues.

But, Mr. Gardner, patients with substance use disorder who are currently using illegal drugs, I believe -- I understand to be the case are not protected by civil rights laws, such as ADA, that protect those with disabilities from employment, housing, and other types of discrimination. The legislation before us includes antidiscrimination language, does it not?

Mr. Gardner. That is my understanding.

The Chairman. And regarding protections for patients seeking substance use disorder treatment, does this language strengthen or does it weaken the statute behind 42 CFR part 2?

And can you turn on your mike? I am not sure it is --

Mr. Gardner. Yes.

Thank you for the question, chairman.

My understanding is that, although I am not a lawyer, is that it would strengthen protections for the use of such information in criminal proceedings, which I think is important.

The Chairman. Well, that is my understanding. And like you, I am not burdened by a law degree. I just try and do public policy. No offense to my -- those who have passed the bar or stopped in there.

Mr. DeLoss, can you identify the legal mechanisms, if any, in this legislation for substance use disorder treatment records to get into the hands of landlords, law enforcement, and civil and court judges without patient consent or a court order?

Mr. DeLoss. No, there is no possible way to do so under this bill. This bill would prohibit those types of disclosures. The disclosures would only be allowed for purposes of treatment payment operations. Does not include any of those third parties. Those third parties are not -- do not fall under the definition of a HIPAA-covered entity, so those third parties would not receive that information. Only certain healthcare providers, not all healthcare providers, are governed by HIPAA. So they would not -- not all healthcare providers would receive the part 2 information under this bill. They would be restricted,

health plans and health care clearinghouses.

So, in addition to those restrictions against the third parties receiving the information, as you have mentioned, there are heightened antidiscrimination provisions.

The Chairman. Heightened. Stronger. More than exists today

Mr. DeLoss. Much more stringent, much more protective than current part 2 protections with respect to antidiscrimination in housing, in employment. Protections against use of any of this information in any kind of proceeding, civil, criminal, or administrative, all of this is far greater in terms of its protections than what part 2 currently provides.

The Chairman. So, if it can't be used to discriminate against you in your employment, your housing, any criminal case, anything else, what is the only thing it can be used for?

Mr. DeLoss. Well, it would primarily be used for treatment. As we have heard, coordinating care is the biggest issue that these SUD programs are facing, is trying to integrate that care with HIEs, health information exchanges, accountable care organizations, any kind of integrated healthcare environment under the Medicaid program. All of this requires coordination.

And with respect to the ability to share that information, the issues that have arisen are so complex in terms of trying to comply

with part 2 that these independent entities, these ACOs, these HIEs, these are not vendors. These are entities that are created to coordinate care. They have refused to allow part 2 information to be included.

I have worked with several HIEs or healthcare networks that have refused to include this information exactly because of the part 2 restrictions. And despite many efforts to create workarounds or ways to address these issues will not include that information.

The Chairman. So I was in a federally qualified healthcare facility in my district, Klamath Falls, Oregon, last week. And we talked about this very obstacle to quality healthcare. And that is all they care about is the patient and quality healthcare. And they said, "Please, please, please."

I said, "42 CFR part 2."

And they said, "Yes. You have no idea what an obstacle that is to patient safety and treatment."

And so that is why we are here. We want to get it right. We appreciate all the panelists today sharing their opinions. This is important stuff. It is not easy.

And, Mr. Chairman, thank you for holding this hearing. I think it has been very, very helpful.

Mr. Burgess. And we thank the chairman.

The chair now yields 5 minutes for questions to the ranking member of the full committee, Mr. Pallone of New Jersey.

Mr. Pallone. Thank you, Mr. Chairman.

I want to thank all the witnesses for joining us.

And, Dr. Clark, I am interested in learning more about the uptick of substance use disorder treatment in the U.S., so I am going to start with you.

In your testimony, you note that, of the 28.6 million people who misuse illicit drugs and the 65 million people who are binge drinkers in the past month, only 3.8 million people received treatment in the past year. Could you explain some the reasons people don't receive treatment for substance use disorder? And quickly, because I have more questions to ask you.

Dr. Clark. Sure.

A number of reasons. The first reason is the ability to pay. The second reason is people don't want to stop. The third reason and fourth reasons are people do have concerns about privacy and stigma. It is an issue that drives people's motives.

And as I pointed out in my 5 minutes and response is that we need to get people early and -- before we wind up having to deal with them later in their substance use.

Mr. Pallone. All right. So, for you and also Ms. Metcalf, could

you explain why maintaining part 2 protections is important to individuals seeking treatment for substance use disorders, including opioid use disorder? Briefly, again.

You could start, Dr. Clark, and then we will go to Ms. Metcalf.

Ms. Metcalf. Yes. Thank you.

42 CFR is important to people seeking treatment because they are assured, when they come to treatment, they have that conversation about who will receive their information. And they have a choice to sign it. And it is a simple conversation. And so it is important to actually to build -- empower those individuals to be part of their care. And it enables that -- it allows them to make that choice that their physician or other -- the individual -- people involved with their medical care can, you know, have the information that they are in treatment.

If they choose not, there are many, many, many, reasons why they might choose not to. For fear in small rural communities where they just choose not to share that they have gone to treatment for their alcoholism, been in counseling. Lots of reasons why they may choose to not share that with a small town family physician that is their physician.

Mr. Pallone. All right. Let me move on.

Under the proposed legislation, patients would lose the right to

determine the extent to which their patient record is shared for treatment, payment, and healthcare operations but receive added requirements related to the use of their part D record in criminal, civil, and administrative proceedings as well as discrimination by lawful holders of part 2 information.

Again, either Ms. Metcalf or Dr. Clark, could you explain why the extra protections included in this proposal do not cure your concerns about eliminating part 2's patient consent requirements.

I guess he is asking for you to speak, Ms. Metcalf.

Ms. Metcalf. The added protections, I think that we are still seeing -- you know, one of our constituents, a member of Faces and Voices of Recovery, has shared her story about unlawful sharing of her medical records, unlawful redisclosure. The impact on her lifelong is that -- an inability to start her small business as a result of the -- unable to purchase group health plan for prospective employees based on her health history of substance use disorders; despite being her primary breadwinner, unable to buy life insurance policy to protect her family based on her health history of substance use disorders; and unable to obtain disability insurance due to the same.

So this -- the bill does not protect these individuals from those who the health insurer will share that information with, which includes extensions of their -- the companies that are related to life

insurance, disability insurance, and so on.

Mr. Pallone. All right. Let me ask one more question, Dr. Clark.

Due to the concerns you have expressed with eliminating part 2's patient consent requirements, what actions can Congress take to allow patients to further benefit from the health system's coordinated care arrangements and still maintain part 2 protections?

I will ask you that one directly.

Dr. Clark. One of the things that we would encourage the Congress to do, or I would, is to facilitate the acquisition of electronic health records by the Substance Use Delivery System, which, incidentally, is not primarily populated in hospitals or in doctor's offices. It is primarily populated in small recovery-type oriented behavioral health treatment systems. So, by the time you reach the doctor's office, your problems actually are much more severe. So you could do that.

And one issue that is missing from this is the issue of child custody. There is no discussion about that in the bill. So, while it says you can't use it about a plaintiff, it doesn't say you can't use it about a defendant.

So these are kinds of things that need to be deconstructed from the bill so that it can enhance the issue of protection if that is what the -- your will is.

I applaud the effort to address these issues. I don't want to suggest that the bill, because of its weaknesses, is -- it has got a bad intent. I think it is a well-intended bill, but I think it is inadequate for the purpose that we need to look at these things more carefully. And I really applaud the Congress' interest in trying to correct some of these problems.

Mr. Pallone. Thank you.

Thank you, Mr. Chairman.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair would just observe for the record that I did vote against the HITECH Act.

Now I would like to recognize the gentleman from Texas, Mr. Barton, 5 minutes for question.

Mr. Barton. Thank you, Mr. Chairman.

And I want to appreciate you and Chairman Walden honoring your word at the markup where this bill was not marked up, but you promised to hold this hearing. It is good to follow regular order and try to get more information.

I come at this a little bit differently than most of the Republicans on this committee. I am the co-chairman of the Privacy Caucus here in the House and have been for the last 10 or 15 years.

I want to read a very brief part of the majority memo for this hearing. It is on the second page of the memo, and this is a direct quote: Part 2 regulations provide stronger protections for substance use disorder treatment records than do most other Federal and State health privacy laws, including the standards for privacy of individually identifiable health information, parentheses, privacy rule, under the Health Insurance Portability and Accountability Act of 1996, parentheses, HIPAA. Repeat: Part 2 regulations provide stronger protection -- stronger protection -- than do most other Federal and State health privacy laws.

That is the crux of the issue. Nobody disputes these tragic individual stories. The gentleman from Ohio, the gentleman that I think is representing Betty Ford whose mother had a problem. Nobody disputes that.

But part 2 protects and -- provides stronger protections for individuals. Most Federal laws don't. You know, a lot of the so-called privacy protections that we have now in Federal law are jokes. They are information disclosure laws that, when a breach happens, the group that is allowed the breach has to notify you that your data has been compromised. They don't protect privacy. They just require the group that let the privacy be abused to disclose you that it has been abused. And in some cases, especially banking, it is not that it has

been breached. They just have the right to use the information however they want as long as they tell you.

So here we have a law that actually does provide privacy protection. And in the name of better healthcare, we are trying to breach it. You know, I am opposed to that.

Now, I am not opposed to some change in part 2. I am -- I understand. But I am opposed to just unilaterally overriding the individual's right to privacy by requiring written consent.

Now, I want to ask the gentleman from Ohio, Mr. McKee. Was your brother, to your knowledge, ever asked to waive his right to privacy under part 2?

Mr. McKee. Not that I am aware of.

Mr. Barton. Okay.

What about you, Mr. Gardner? Was your mother ever directly asked to waive her part 2 rights?

Mr. Gardner. I cannot answer for sure.

Mr. Barton. Okay. You know, it may be they were never asked. It may be they were asked, and they refused to. We just don't know.

Mr. McKee. Congressman Barton.

Mr. Barton. Yes.

Mr. McKee. With all due respect, how would the physician known to have asked?

Mr. Barton. What is that?

Mr. McKee. How would the physician, how would the surgeon, have known to ask?

Mr. Barton. Well, if I were treating, and I am not a doctor, but if I were treating your brother, I know, when I go to my dentist, when I go in for any kind of a procedure -- I have had gallbladder surgery; I had a heart attack -- I have to fill out a form three or four pages long that has asked if I have ever been treated for any of the following occasions. And I believe that, if I were a prescribing physician giving fairly strong pain medication, I would probably either informally, verbally, or formally ask that question.

Now, I am -- you know, I just know -- in fact, every time I go to my doctor, I have to fill out the same form again. And I say, "Well, I just filled it out last year."

"Well, I am sorry. You have got to do it again."

So, you know, there are cases -- and my time is about to expire. There are cases where maybe the patient is not mentally able to make a decision. But my guess is a vast majority of the time they are competent, and they choose not to disclose for their own purposes. Now, I don't know that. That is just a supposition.

Anyway, I had two more questions I will submit for the record, Mr. Chairman, since my time has expired.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Barton. And thank you all, the witnesses, for being here.

Mr. Burgess. The chair thanks the gentleman. The chair recognizes the gentleman from Maryland, Mr. Sarbanes, 5 minutes for your questions, please.

Mr. Sarbanes. Thank you, Mr. Chairman. Thanks to the panel.

I can't see -- all the way on the end. Yes.

Mr. DeLoss. Mr. DeLoss.

Mr. Sarbanes. Sorry. I lost track of the witness list.

You, I think, were describing, in the new proposed draft of the bill that has been mentioned here today, that there is some antidiscrimination language in there. And I guess that would make it illegal for any entity to use records to discriminate for healthcare, hiring, employment, sale or rental of housing, access to courts, recipient of funds, et cetera. And that gives you some confidence -- increased confidence that facilitated sharing of information that is suggested by the proposed bill would mitigate the occasion for discrimination, therefore, potentially be less stigmatizing. So it goes to addressing that issue. Is that right? Is that the idea?

Mr. DeLoss. That is correct, yes.

Mr. Sarbanes. Yeah. And I get that.

What I worry about is that -- that is well and good. But it is

kind of like the cow is out of the barn. In other words, once the data is out there or the information is shared, it may be that somebody misusing it is subject to some kind of penalty or prosecution or what have you. But as we know in life, a lot of times, that kind of discrimination can go unpunished, and at that point, the information is out there. So a better protection is to keep the information safe or in close hands before it even gets out there and you have to test the proposition of whether people are handling it properly.

So I think, while I get -- I see why people are pointing to that and suggesting, "Well, that should give us comfort," I am not sure it gives the comfort you are suggesting to a patient who is going to say, "Well, that is fine if someone could get in trouble if they misuse my information, but the chances that it could get misused are still pretty high, and they might not get penalized for it, and there may be no deterrent effect as a result, so the better path for me is to just not share the information, or that puts me in an exposed position."

So I just wanted to make that point, because I think it is a fair one. And I wanted to turn to you, Ms. Metcalf, and just ask you --

Mr. DeLoss. Could I quickly respond?

Mr. Sarbanes. Yeah, you could.

Mr. DeLoss. Thank you.

The issue that I see in response to those concerns, which I think

are valid, is that the current part 2 regulations, even though there is a consent process, because they are so overly stringent and technical, it doesn't allow the patient to make that choice, because the recipients, such as HIEs or ACOs or these integrated care environments that are part of the new healthcare model, would not accept that information.

So, even if the patient made the choice to share the information, it couldn't be accepted because those entities would refuse it. In addition, the recipients would have to segment that data if they did receive it so it would not be redisclosed. Again, something that certain electronic health records do not have the current capability to do.

And in addition, with respect to the bill itself, in addition to the antidiscrimination provisions you mentioned, there is a limited set of recipients that could receive this information so it is not going out to third parties. It is not going out to billing agencies. It is not going out to marketers. It is not going out to businesses --

Mr. Sarbanes. Let me jump in, because now I am down to 14 seconds. So I won't to ask you this question, Ms. Metcalf.

Mr. DeLoss. Thank you.

Mr. Sarbanes. But I -- my understanding is that, even keeping the key components of the part 2 regulations in place, that through

education, through finding ways of streamlining some of the technical obstacles that people are concerned about, that we could improve the situation for coordinated care without compromising the concerns people have about the privacy of the data. So that is why I continue to have some misgivings about the proposed legislation here that we are talking about.

With that, I will yield back.

Thank you.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentleman from Kentucky, Mr. Guthrie, 5 minutes for you questions, please.

Mr. Guthrie. Thank you very much, Mr. Chairman. Thanks for having this meeting.

The first few questions are for Mr. DeLoss. I am going to try to ask some on behalf of my good friend from Texas, Mr. Barton.

But, first, Mr. DeLoss, it is my understanding that part 2 only applies to federally supported providers who identify themselves specifically providing SUD treatment and referrals. Are there health providers, say office-based physicians, prescribing buprenorphine or for-profit providers that do not fall into this category and do not have to comply with part 2?

Mr. DeLoss. That is correct. There are certain providers that do not have to comply with part 2 because either they don't -- are not federally assisted or do not hold themselves out as specializing in this area.

Mr. Guthrie. So what about the Department of Veterans Affairs? And does it make sense that some patients with substance abuse disorders will have this information in their medical records and some will not?

Mr. DeLoss. With respect to the Department of Veterans Affairs, that would be an exclusion from the coverage of part 2. Part 2 would not apply to those records.

Mr. Guthrie. Does it make sense that some would have this information and others would not?

Mr. DeLoss. No. It leaves an incomplete record. Absolutely.

Mr. Guthrie. So, while part 2 is supposed to have stronger protections, Mr. DeLoss, can you discuss the enforcement authority for part 2 infractions in comparison to the enforcement authority for HIPAA violations?

Mr. DeLoss. Yes.

Part 2 is a criminal statute, so the enforcement, in addition to the Substance Abuse and Mental Health Services Administration, SAMHSA, there would be a criminal enforcement through the Department of Justice. To my knowledge -- and I know Dr. Clark had a differing

opinion. To my knowledge, there has never been a substantive enforcement action taken for a violation of a part 2 provision in its history.

With respect to HIPAA, you have the Office for Civil Rights, Department of Health and Human Services, that would engage in a process of audits, reviews, complaint-driven responses, investigations. You have the breach notification provisions which are now part of part 2 under the bill. I did not mention that earlier. All of that results in a very comprehensive enforcement scheme. And I believe the most recent information I have is that over $75 million in fines and penalties have been levied against those that have violated HIPAA or not complied completely with respect to the protections that that law requires.

Mr. Guthrie. Okay. And I am going to ask a question on behalf of my friend from Texas he said he didn't get it to, so I am going to read it.

Substance use disorder treatment records -- and this is for Mr. DeLoss -- has already been subject to data breaches. For example, in August 2016, an addiction treatment provider in Baltimore was hacked, and patient addiction treatment information was put up for sale on the dark web.

In 2017, a data breach of Bronx Lebanon Hospital Center in New

York calls the release of at least 7,000 people's records, which included addiction histories.

So, that said, under part 2, are there currently breach notification requirements?

Mr. DeLoss. Correct. The HIPAA breach notification requirements would require notification not only to the individual patients, probably in the cases you mentioned, to the media as well as the Department of Health and Human Services.

Mr. Guthrie. Under part 2, what are the penalties for an unauthorized disclosure?

Mr. DeLoss. Well, they can range from $100 for a small negligible type of violation up to $1.5 million.

Mr. Guthrie. So how would the legislation before us help patients whose addiction treatment data has been compromised?

Mr. DeLoss. Well, there would be a requirement and affirmative duty to report any type of breach or violation under the breach notification provisions. Part 2 does not currently require any kind of notification of a violation by a program -- or by a provider. So there would be that new affirmative obligation to disclose that, not only to the individual patient but also to the department as well.

So that would obviously bring up the ability -- or heighten the ability to enforce the law, because it would impose an affirmative

obligation to do so.

Mr. Guthrie. Thank you. And I have about a minute.

So, Mr. Gardner, I have a -- the Assistant Secretary for Mental Health and Substance Use, Elinore McCance-Katz, wrote recently in a letter that, and I will read a paragraph from her letter, the practice of requiring substance use disorder information to be more private than information regarding other chronic illnesses, such as cancer or heart disease, may in itself be stigmatizing. Patients with substance use disorders seeking treatment for any condition have a right to healthcare providers who are fully equipped with the information needed to provide the highest quality of care.

I have 30 seconds, Mr. Gardner. Do you agree with that statement?

Mr. Gardner. That is a big subject for 30 seconds, but I do believe that, over the course of time, a paradigm of separation and secrecy as opposed to integration and openness does, indeed, create a culture that -- where stigma lives.

Mr. Guthrie. Well, thank you, and my time is expired.

And I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentlelady from California, Ms. Matsui,

5 minutes for your questions, please.

Ms. Matsui. Thank you, Mr. Chairman.

I want to thank all the witnesses for being here today.

Mr. DeLoss' testimony highlights that, under this bill, a part 2 provider could still require additional consent if it wanted to. There may be a way for this bill to reflect that option more directly. I recognize that Mr. McKee's brother story is an all too common scenario in which the patient may have not chosen to consent even if sharing the information will be in their best interest. However, I think the big question we must ask ourselves is whether we want to completely take away that right to consent.

I think middle ground here is retaining some ability for the patient to consent to whether or not the information is shared. Under current part 2 law, the patient has a right to consent either every time their information is shared or, under new SAMHSA rules, more broadly if they chose. Under the current bill we are considering, a patient's information would be shared automatically with covered entities for the purposes of treatment, payment, and healthcare operations when they choose to be treated.

What if, upon seeking treatment, the patient retained the right to consent and could choose between privacy protections under 42 CFR or under HIPAA?

Dr. Clark, I will start with you, but I would like to hear from the other witnesses as well.

Dr. Clark. As I mentioned, I applaud the efforts of this committee to address some of these critical issues, because they are of great concern to our Nation's public health and to the citizens of this country.

You raise an important point that, essentially, already exists, has already been acknowledged. There are -- you can strengthen 42 CFR part 2 by strengthening the penalty without abandoning the confidentiality and right to make a personal decision.

There are conflict of laws issues that are raised by the current bill that will have to be negotiated, because, indeed, it attempts to abrogate things like the ADA, the DOT, and Department of Justice kinds of rules.

So then there is the issue of competency of individuals. If you remove an individual's competency in this situation automatically, then what about for cancer? What about for other conditions?

So the right to choose what happens to your own person is an important right. And what we are talking about is creating a slippery slope where we nullify that right for this condition, and then we have to nullify that right for another condition. So I think we need to keep that in mind. Addressing the conflict of laws, addressing the

issue of penalties, and making sure that we understand the covered entities.

Ms. Matsui. Okay. Any other comments to this at all?

Mr. DeLoss. I can respond briefly.

Ms. Matsui. Yes.

Mr. DeLoss. In terms of requiring the consent, I believe that one of the issues would be in what situation would consent be required. Even with the changes that were made in the regulations in 2017 to 2018, there are still issues exchanging that information directly with other healthcare providers because of the limitations that are imposed and because of the complexity of those regulations.

And I think that probably really sums up the critical issue, which is, because of those complexities, that health systems, medical groups, hospitals, and others cannot comply with, the HIEs, ACOs, et cetera, this information is not being included in those exchanges of information for purposes of care coordination. So a consent by itself does no good. But if you add the layers of complexity that are in place currently under the law as well as others that have been proposed by the opponents to this bill, then it makes it extremely difficult, if not impossible, to share that information.

Thank you.

Ms. Matsui. All right. Now, I realize that both HIPAA and part

2 protect against information be shared with landlords, employers. But I am concerned that the definition of covered entity under HIPAA may still be too broad such that it increases the likelihood of a breach.

Mr. DeLoss, under this bill, could information only be shared between treating providers, or could it be shared between two covered entities that are not necessarily treating the specific patient?

Mr. DeLoss. The information could be shared for treatment payment or healthcare operations only between two covered entities. A part 2 program and a covered entity and then a covered entity with another covered entity downstream and definitely, correct.

Ms. Matsui. I heard differing opinions on whether H.R. 3545 allows for disclosures to business associates.

Are business associates not covered under payment treatment and operations under HIPAA?

Mr. DeLoss. It is my interpretation of H.R. 3545 that the bill would not allow disclosure to business associates because they are not, quote/unquote, "covered entities," correct.

Ms. Matsui. Okay.

Mr. Chairman, I yield back. Thank you.

Mr. Burgess. Does the gentlelady yield her time to me?

Ms. Matsui. Yes, I yield to you.

Mr. Green. I thank my colleague.

Mr. Chairman, you and talked about this. I would like to ask. Mr. DeLoss testified that the bill would not allow information to be shared with business associates. However, a Republican memo states, quote, the discussion draft will permit said records to be shared between covered entities, healthcare providers, payers, and business associates.

I would like to see if Mr. DeLoss can clarify as to the intent to just include entities, or is it also the intent to include business associates?

Mr. Burgess. Before we go into that, it is not Mr. DeLoss' -- it is not required of him to --

Mr. Green. Oh, no. He doesn't have to. I would just like --

Mr. Burgess. -- to justify what is in the majority memo. He is responsible for his testimony. We are responsible for ours.

You are welcome to address that if you would like. But you are not required to.

Mr. DeLoss. Again, it is my interpretation -- I am not familiar with the memo, and I -- it is my interpretation that, because it allows for disclosures from part 2 programs to covered entities or by covered entities to covered entities, that business associates would not be included. That is my interpretation.

Mr. Green. Thank you. I just wanted to get the --

Mr. Burgess. Thanks. The gentleman yields back.

The chair recognizes the gentlelady from Tennessee, Mrs. Blackburn, 5 minutes for your questions, please.

Mrs. Blackburn. Thank you, Mr. Chairman.

And I thank you all for your patience in being here today and talking with us about this issue.

As you know, we had quite an extensive hearing prior to your hearing today with the drug distributors and looking at the opioid issue and their participation in it. So this is an issue that we take very seriously.

And as Chairman Walden said, one of the things we have heard from families, from recovering, those that are recovering from addiction, that have suffered from addiction, is wanting to have visibility into those records so that they could be there to help their family member or their loved one.

And we were -- Ms. Matsui was just touching on the consent forms. And I want to go back to that issue but take a little bit different tack with this. Because I was talking with an attorney yesterday, and we were talking about someone they were trying to get into drug court and a treatment program. And this person had looked at this attorney and said, "You can take me to drug court. They can send me to detox. But I am not going to stop using."

And he talked about the heartbreak. And I think many of us, and you all, Ms. Metcalf, your situation; Mr. McKee, with your brother; Mr. Gardner, with your mom, those are the heartbreaking, heart-wrenching situations that those -- as a mom and as a friend to people who have dealt with this, it just tears you apart. And we realize that.

Ms. Metcalf, I want you to just say what would it have meant to you if there was somebody else that had that visibility -- and, you know, we know -- we hear from doctors about compliance or about people not telling -- maybe telling the truth but not the whole truth when they come in and have a discussion about their health. What would it have meant to you to have somebody with the visibility that could say, "You need to sign this consent form; you need to be truthful and honest about this"?

Just give me 30 seconds on that.

Ms. Metcalf. Absolutely. Thank you.

And it meant an awful to me. I had a physician and my mother that said -- when I was 17 years old, worked together to coordinate my care. And I signed a consent form, because they -- my counselor said that this would be a good thing, to work together as a team. I was prescribed Antabuse at the age of 17, because I was drinking excessively and had been to treatment twice. And so they coordinated together.

It made a lot of sense to me to work together, and I consented and signed that form as a 17-year-old. I would do it again as I -- because I was educated in that I was given the opportunity to make a choice.

Mrs. Blackburn. Now, as you work with those that are recovering, how do you counsel them?

And, Mr. Gardner, I want you to come in right behind her on that answer.

How do you counsel people on signing a consent form?

And, Ms. Metcalf, you first, and then Mr. Gardner.

Ms. Metcalf. I worked as an intake worker in a residential treatment program and had those conversations many, many times. It was a very validating experience to have to say this is -- this is what that form is, 42 CFR part 2. If you would like to share your information with your physician, you can sign it now. Or as you are here in treatment with us, we will revisit this, because you may want to coordinate the care.

I believe that this -- having others make a choice for us or even having this conversation is stigmatizing in a way that says that we don't have the ability or that we are less than, that we don't -- we are not capable of making those choices, and we are. There are millions of people that are making those choices every day and consenting to

sharing information with their healthcare providers.

Mrs. Blackburn. Would you say that consenting to share that information and get that helped save your life?

Ms. Metcalf. I don't know that. The prescription that I was given didn't save my life. It didn't work for me. I didn't go on -- I went on as an adult to treatment.

Mrs. Blackburn. Okay.

Mr. Gardner.

Mr. Gardner. Thank you for the question.

I do think those are compassionate conversations. I will say that I don't think patients generally have an expectation, come in with some expectation or knowledge of part 2, some difference between HIPAA and part 2. They have some general expectation of privacy, for sure. And I will say that when we come back for repeated consents, in the real world, that is sort of annoying, frustrating sometimes, and can actually raise alarms, like what wasn't I thinking about that I need to be thinking about now?

Mrs. Blackburn. Okay. I yield back.

Mr. Burgess. The chair thanks the gentlelady.

The chair recognizes the gentlelady from California for 5 minutes for questions, please.

Ms. Eshoo. Thank you, Mr. Chairman.

And thank you to all of the witnesses.

I have had the advantage of being able to not only listen to your testimony but also to listen to all of the questions from members on both sides. And there are enormous complexities in this. I don't really think there is a tidy answer to this. And I say that because I keep thinking of my first cousin who suffered all of his life from mental health issues, from the time he was in his early 20s until he passed away maybe about 6 months ago. And he didn't really fit into what we are talking about here today in many ways, because if you said to him, "Give consent," he really would not have known what he was talking about. He wasn't in a position to do that.

So I want to thank Dr. Clark. He is a part of a great university in my region, Santa Clara University. It is a Jesuit college with a graduate school, and it is highly regarded for many of its graduates, one of them a member of Congress, a son of the House, Leon Panetta. So thank you for being with us.

What I would like to know is, from amongst yourselves, what would -- Mr. Gardner, what would you and Mr. McKee say to Ms. Metcalf? Ms. Metcalf, what would you say to them?

You believe that part 2 is necessary, but they -- and you told your story, and it is an important one. They told their stories. They are an important one.

What is lacking in HIPAA? Where is the danger going to come from if we change this? So --

Ms. Metcalf. Yes.

Ms. Eshoo. -- maybe the three of you, in a minute, tell me why your case, you believe, is the strongest.

Ms. Metcalf. I will go.

And I wanted to say that, you know, we hear these stories, and it is very impactful. I think that when a patient -- or when a person with a substance use disorder wants to share their information with a family member, they will. I don't know that signing a HIPAA is going to allow them to -- or is going to help that. I think that the family member doesn't have access to that information.

Ms. Eshoo. See, the thing -- and what you are saying to me is, and maybe my -- my own experience is discolored by the fact that my cousin really was not capable. I mean, if he said so, he sounded and he looked very clear, but he really didn't know what he was talking about a good part of the time. So is that what we are relying on?

Ms. Metcalf. I think we have a very misconstrued image of what alcohol and drug addiction is. There are millions of us -- 23 million in recovery. There are individuals who go on to live and overcome addiction. We don't -- we are not --

Ms. Eshoo. And this applies only to alcohol and drug abuse?

What we are talking about today, it only applies to those two addictions? It only applies to those two addictions?

Ms. Metcalf. Yes.

Mr. McKee. You know, I would say that by enshrining this distinction between medical and surgical care and substance use disorder conditions that, in the Federal code, we are simply adding to the stigma in a structural way.

You know, there are other health conditions that are highly stigmatized, like sexually transmitted infections, HIV/AIDS. Why are we separating out substance use disorder information?

You know, I work for NAMI. There are a lot of folks that we represent that are seriously mentally ill.

Ms. Eshoo. That is an extraordinary organization. I worked with them for years. They really are outstanding.

Mr. McKee. Thank you, Congresswoman. We appreciate that very much. And there are a lot of folks with serious memory illness, like your brother -- or your cousin, who simply don't understand this process. And yet their treatment providers of either mental health provision or medical/surgical care are still blocked from seeing these things.

I mean, it is almost as if we are --

Ms. Eshoo. Let me give Mr. Gardner just a moment. I appreciate

what you are saying.

Mr. Gardner. Yes. Thank you.

I think in the specialized addiction treatment field, we have recognized for a long time that the way to -- one of the big opportunities to improve the way addiction is addressed in America is to get all of healthcare involved and not have it be just us in the specialty treatment field.

And so every opportunity I think we can get to bring healthcare into the fold and get more eyes and professionals on this disease for the people that suffer from it, I think the better. And this seems like an opportunity to do that.

Privacy is important is what I would say. There is no doubt about it. I just think the strategy that we had in the seventies of trying to avoid discrimination is no longer the right strategy. We should be confronting discrimination, and I think we have with -- in HIPAA and the newly -- the new language around part 2 that we enforce discrimination and still bring healthcare into the fold.

Ms. Eshoo. Thank you very much.

Thank you, Mr. Chairman.

Mr. Burgess. The chair thanks the gentlelady.

The chair recognizes the gentleman from New Jersey, Mr. Lance, 5 minutes for your questions, please.

Mr. Lance. Thank you very much, Mr. Chairman.

And good afternoon to the panel.

I will be introducing a bill that will target new resources for substance use disorder. Health homes, as I understand it, they currently exist in four States: Maine, Maryland, Rhode Island, and Vermont.

Under the model of care in Vermont, for example, the State has markedly expanded access to medication-assisted therapy; reduced the use of alcohol, opiates, and other illicit drugs; decreased the use of hospital emergency room departments; reduced illegal activities and run-ins with law enforcement; and substantially improved family life, housing stability, and emotional health.

However, according to a January 2015 bulletin put out by CMS entitled "Designing Medicaid Health Homes for Individuals with Opiate Dependency: Considerations for States," one barrier to effective treatment in care coordination identified by Vermont and other participating States was 42 CFR part 2, and I quote, "Collectively, the three States cited Federal confidentiality requirements as a barrier to effective integration of care and sharing of vital information between the health home and other medical professionals," closed quote.

And, Mr. Chairman, I ask that the CMS study be submitted to the

record.

Mr. Burgess. Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Lance. Thank you, Mr. Chairman.

I know that you don't know the particulars of my bill, but it seems like a way forward. And that would be to align part 2 with HIPAA. And I think that people on the ground tend to agree with this.

Mr. DeLoss, would aligning part 2 with HIPAA eliminate the barrier to effective integration of care in sharing of vital information between the health home and other medical professionals? And what sort of improved outcomes for patients could we expect to see if this were the case?

Mr. DeLoss. Well, again, without seeing the bill, but based upon your description, it would appear to me that aligning HIPAA with part 2 would allow for the free flow of information between those entities as well as substance abuse and substance use disorder part 2 programs. So that would coordinate the care, allow that information to be shared for the betterment of the quality of the care as well as ensuring that there is no -- any type of drug that could interact negatively with anything that the individuals currently taking in the form of MAT or what they may, as mentioned earlier, as far as their addiction itself.

RPTR BRYANT

EDTR SECKMAN

[3:30 p.m.]

Mr. Lance. Thank you.

Is there anyone else on the panel who would like to comment?

Yes, Dr. Clark.

Dr. Clark. I would like to remind people that most substances don't have medications available to treat them and that we are talking about essentially blaming individual autonomy and rights for the failure of the HITECH Act, the failure of practitioners to be adequately trained to address the issue of addiction. So we are blaming the very people we are trying to help for the weaknesses of the delivery system.

You just had a hearing this morning. You had people throwing large amounts of drugs into the delivery system without question, making money hand over fist, and no one questions that now. We recognize: Oh yeah, we should have recognized that large numbers of pills going into a community might be a problem.

We have heard of physicians just writing prescriptions without recognizing that this is an issue.

I treated patients a long time ago, and we always asked: Do you want your family involved? You need your family involved, because this

is a family disease. It is not just your own individual disease.

So what we are talking about is not dealing with the system; we are talking about blaming the victim. And I encourage you to look at part J of this bill 3545, which says: to develop and disseminate model training programs for substance use disorder patient records, to get people, to make sure we have enough pilots to prove the point rather than to speculate the point. Because once the horse has left the barn, you can close all the doors you want, but you don't have the horse.

Mr. Lance. Thank you. Others on the panel?

I commend to your attention the bill that I will be introducing, and I certainly would like you to examine it for your expertise. This is an issue that knows no bounds here in Congress. It is an issue on which we hope to work in a bipartisan capacity and also in a bicameral fashion, because obviously, we want to improve the system together.

Thank you very much, and I yield back the balance of my time.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentlelady from Florida, 5 minutes for your questions, please.

Ms. Castor. Thank you, Mr. Chairman and Mr. Green, for organizing this hearing today. And I would like to thank all of the witnesses for being here, especially for those of you who have shared

very personal stories. Thank you very much.

Ms. Metcalf, I would like to get a better understanding of the importance of part 2's patient consent requirement. What role does getting patients' consent to disclose their substance use disorder treatment information to providers and other entities play in their treatment? And why is this patient consent requirement important for individuals with substance use disorder?

Ms. Metcalf. I would like to respond to that. What we find with people in active addiction is that they are using very little healthcare services for preventive care. They are not getting treated for the conditions that are underlying. They are not doing things that are healthy and seeing dentists or -- you know, there are so many things that can be done to help that person.

Once they engage in treatment, that conversation about their health and wellness, taking care of those things to help them live better and longer lives, it happens because the counselor talks to them about the value of sharing that information with their physician. And we have seen, you know, incredible life improvements of people in recovery when they are able to do that.

That is a process that takes place that initially people are not generally --

Ms. Castor. Is there data on that? Are there studies you can

point on?

Ms. Metcalf. I have studies of people in long-term recovery, the Life in Recovery Survey that indicates what recovery does for people. It helps them engage in those medical services where they weren't before. And the services they were using before were the higher cost emergency department services or treatment services versus the preventive care where they could be going to their physician.

Ms. Castor. What should providers do if substance use disorder patients refuse to give their consent to disclose their patient information to other health providers?

Ms. Metcalf. They should continue to have that conversation with them; and when they are ready and they see the value of that, they will do that in most cases.

Ms. Castor. Because the relationship between the patient and the provider is critical, especially with folks with substance use disorder. The cornerstone of the relationship, of course, is trust, which includes trust that the information you give to your provider will be used appropriately and that you know how it will be used.

According to one recent study, two-thirds of adults in America are concerned about a breach in the security and privacy of their personal health information. In addition, the study showed that over 12 percent of patients withheld information over privacy concerns.

The more concerned you were about privacy, the more likely you were to withhold information. And I am hearing that this is called your privacy protective behaviors. There has got to be a simpler term for that.

But, Dr. Clark, for people with substance use disorders, you know, all of you know that that relationship is important between the patient and the provider. Would you say that people with substance use disorders are particularly sensitive to concerns about how their data would be used?

Dr. Clark. That has been my clinical experience. But, as Ms. Metcalf pointed out, the job of the professional in the treatment arena is to encourage individuals to recognize the importance of comprehensive interventions. And that way, they can sample the kinds of reactions that they get. I have heard people in other settings who are in recovery point out that they, in fact, were dropped by practitioners for what appears to be essentially manufactured reasons.

You can't determine whether you have been discriminated against. You just know that these practitioners are unavailable. The problem with the HIE notion is that you may have hundreds of thousands of entities who have access to that information, and they get to decide whether they want to see you or not, and they don't have to see you.

Ms. Castor. But Mr. DeLoss I thought made some good points -- and

I note you are sitting right next to him and heard -- that this is very narrow and could be helpful when we are talking about the covered entities. You heard what he said and how narrow it is and why it doesn't --

Dr. Clark. Okay. I disagree with his definition of how narrow it is. Remember, this is your bill, not his bill. So his interpretation won't control. Your interpretation will control. You are making this. He doesn't get to talk about legislative history. He gets to litigate it if that is an issue.

Ms. Castor. We are building the record. We are building the record here.

Dr. Clark. But I point -- so some of the statements he has made in terms of like third-party notification, 42 CFR part 2 does report third-party notification. You do have to go through extra steps, but it does permit third-party notification. So he was wrong about that, so he is probably wrong about whether the covered entity construct is as limited as he thinks it is.

So we have to think about that collectively rather than just sort of extemporaneously make a declaration.

Ms. Castor. I wish I had time to allow him, Mr. DeLoss, to respond, but maybe another member could ask about that.

Mr. Burgess. I think we should allow Mr. DeLoss to respond.

Mr. DeLoss. Thank you. 42 CFR part 2, to respond directly to Dr. Clark's statement, does not have a duty-to-warn exception.

Dr. Clark. It does have a duty-to-warn exception. It does.

Mr. DeLoss. No, it does not.

Dr. Clark. It does. It permits third-party notification. You should read it a little more closely, sir.

Mr. Burgess. The gentleman from Texas is correct; the witnesses don't get to debate.

Dr. Clark. It is not a debate here.

Mr. Burgess. It is now in order to recognize Mr. Long of Missouri, 5 minutes for your questions, please.

Mr. Long. Thank you, Mr. Chairman.

And, Mr. McKee, one recent study found that physicians continue to prescribe opioids for 91 percent of patients who suffered a nonfatal overdose, with 63 percent of those patients continuing to receive high doses. Seventeen percent of these patients overdosed again within 2 years. How will this legislation before us help to stop overdoses and prevent these deaths from occurring?

Mr. McKee. Thank you, Congressman. Assuming both of my hands are covered entities, it lets the left hand know what the right hand is doing.

Mr. Long. A pretty good explanation, I would say. Do you think

that allowing health providers to see patients' complete medical record when making treatment decisions would help to prevent such tragedies as in the case of your brother?

Mr. McKee. I think it is very likely that improves their odds of surviving.

Mr. Long. Your brother, you said 36 years old at the time he deceased, three children, divorced, living in your mother's basement. You had fought this, he had fought this addiction, your family had fought this addiction for years and years and years.

What can we do, as Congressmen, what can we do here in Washington, D.C., to prevent another 36-year-old brother deceasing such as yours?

Mr. McKee. Thank you, Congressman. H.R. 3545 is a great step. We also have to improve access to prevention, treatment services, ensure that folks are covered, ensure that essential health benefits are maintained, such as those requiring substance use disorders to be covered. And we also have to ensure that we really truly have behavioral health parity in this Nation.

Mr. Long. We have done, of course, had several panels and discussions on this topic here in Energy and Commerce Committee. And a few weeks ago, we had I believe seven family members that had all -- or seven folks that had all lost family members, usually younger college age students and things.

There is one fellow that works here in Washington, D.C. And I was describing at a function one night about how my two daughters, one was 29 -- I better get this right -- and one will be 32 I think in a few more days, but how they had had three friends of theirs that have deceased from opioids. And when we had the panel in here with the seven parents that had lost children and the one lady that was addicted herself and had been since a young, young age.

Is there anything that -- it had to be extremely frustrating dealing with your brother over the years, trying to help him. We had, as I started to say, one fellow that worked here that had a son, as I was describing at this dinner, about his son had just gotten out of treatment for the third time at Christmastime, and they opened packages, and the boy disappeared. And he told his wife, he said, "Well, you know, we need to check in on him." They hadn't heard -- they went upstairs, found him collapsed, as you described, in a fetal position on the floor of the bathroom. In this case, they were able to revive him, got him to the hospital. The next morning, they walked in, and he told his dad, he said, "Dad," he said, "I knew when I got out of treatment I couldn't do the amount of heroin that I had done before," but he said, "My gosh, Dad," he said, "I just had such a tiny bit on the spoon, I could barely melt it."

Is there anything you can enlighten us with that would help these

families that are where you were before they have lost these loved ones?

Mr. McKee. That is a great point. When Brandon called me, he talked about how he had been off opioids for about a week and a half, and he had gotten dope sick. And then he relapsed. He didn't know about medication-assisted treatment or there was enough stigma around medication-assisted treatment that he didn't access it. He was an all-or-nothing kind of guy.

And I think that when you align things like this, 42 CFR with HIPAA, you are simply showing that this is a disease. These are chronic brain diseases. And the public needs to understand that they are no different than HIV/AIDS, diabetes, cancer. The more we have these discussions, the more we break that stigma, just like with mental illness.

Mr. Long. Thank you for sharing your story here today. And thank all of you for being here. And the fellow I was talking about, his son has, since receiving the injection that you get -- I think it is once a month maybe, and it is expensive. It is a thousand dollars a month, but, you know, for people that can afford it, that is fine, those that can't -- but, anyway, thank you.

And, Mr. Chairman, I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentleman from Illinois. Mr. Bucshon, 5 minutes for your questions.

Mr. Bucshon. Thank you very much, Mr. Chairman.

I was a cardiovascular and thoracic surgeon for many years before coming to Congress, and I just want to describe a few personal experiences -- my wife is an anesthesiologist -- with what can happen when you have an incomplete medical record.

You know, I will just describe one patient who is a lady in probably her mid 70s who I did an aortic valve replacement on. She was a nice lady. In her medical history, there was nothing about alcohol abuse. However, the second night after surgery, she went into DTs, jumped over her bed rail, landed on her head. And when I subsequently went and talked to the family, they said, "Well, actually, you know, she drinks quite a bit." I am like, "Well, why didn't you tell us that up front?" It wasn't in her record. We had no idea. She had been in, you know, Alcoholics Anonymous in the past, relapsed. This is a real problem.

You know, I had patients -- and it is not just alcohol or narcotics. I have patients that take dietary supplements for vascular health. Well, let me just give you a little clue. When you have open heart surgery and you are taking medication for vascular health, you bleed like crazy and you won't stop. We had no idea. I have had three

or four patients with that. They didn't tell us. We asked specifically, do you take dietary supplements? Didn't tell us.

And then my wife as an anesthesiologist, and I don't have a specific case, but has routinely had problems anesthetizing patients with narcotic and benzodiazepine-related anesthetic agents, and subsequently has found out from the family, even though the patient denied it, that they chronically use opioids and/or benzodiazepines.

Patients don't tell you these things, and it is a really big problem. We need to know. Physicians, real physicians out there in practice need to know, because it has real repercussions. My patient who jumped over the rail and hit her head subsequently, after about 2 weeks in the hospital, survived her DTs and her aortic valve replacement and her minor concussion, but they may not.

So, Dr. Clark, in your written testimony, you say: The case is often made that healthcare delivery systems need to know about the substance use history of a patient. You don't hear why providers simply can't ask patients themselves about their substance use histories.

Do you really believe that patients are going to tell you about these things, I mean, every patient is going to tell you when you ask them?

Dr. Clark. Well, sir, every patient is not going to tell you

everything about everything. On the other hand, if, in fact, you take the time or you have a staff person who can take the time to establish the rational relationship between what it is that interventionist is going to do, I think you will get more truth-telling than you are aware.

I have found that asking people things in a carefully designed nonjudgmental way gets a better response than simply reading it in the chart and deciding that you may or may not --

Mr. Bucshon. Fair enough. So the thing is you are a psychiatrist.

Dr. Clark. Yes, I am.

Mr. Bucshon. People come to you because you need to ask -- you know, because they have been sent to you to ask questions about mental illness and substance abuse things. Of course, I appreciate your experience, but I can tell you when you are not a psychiatrist and you are just a practitioner, a heart surgeon, an anesthesiologist, in my personal experience, patients do not tell you the full picture.

And it is not a criticism of them. Many people don't know the impact, the potential impact, medical impact of not telling you. You know, for example, why would a dietary supplement be a problem if you are going to have heart surgery? Well, they don't realize the fact that it really does anticoagulate you and you bleed, right, and you have to be transfused. I have had this happen. So I appreciate your

experience, but I would argue that the patients don't tell you, and there are real repercussions.

I mean, the other question is I have is, can you disclose to people's employers or law enforcement people's HIV or mental health status without their consent?

Dr. Clark. Generally not, but it also depends on the context of the situation.

Mr. Bucshon. Right. Okay. So I get that. And there is some context, right? If they are threatening someone or something like that, there are exceptions, right?

So why would you think if there is a history of substance abuse or alcohol abuse in a patient's medical record already covered by HIPAA, why would you think that there would be a high risk of that being disclosed?

Dr. Clark. Well, actually, HIPAA's protection is weaker when it comes to such disclosures. I think 3545 makes an attempt to address that. HIPAA does allow administrative police inquiries. So you --

Mr. Bucshon. Yes, but from what Mr. DeLoss says, you have to have a court -- you can answer that, Mr. DeLoss.

Mr. DeLoss. You need a court order; that is correct.

Mr. Bucshon. What is the requirement?

Mr. DeLoss. You have to have a court order.

Mr. Bucshon. Or the patient has to authorize it?

Mr. DeLoss. Correct.

Mr. Bucshon. Okay. So, you know, what I am saying here is, look, I appreciate your experience on this issue, but what this legislation is trying to do is, honestly, I think, create parity for patients so that medical providers can provide adequate healthcare.

And, you know, the reality is, is that -- and, Mr. Chairman, just a couple more seconds -- is that without complete information, in my personal experience as a healthcare provider, in a medical record, there are potentially serious ramifications of not understanding a patient's complete medical history.

I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

And the chair now recognizes the other Representative from Indiana, the gentlelady from Indiana, 5 minutes for your questions, please.

Mrs. Brooks. Thank you, Mr. Chairman.

And thank all for being here and for sharing.

It is my understanding that individuals with opioid use disorder die, on average, 20 years sooner than other Americans. And it is largely because of a strikingly high incidence of poorly managed

cooccurring chronic diseases, whether or not that might be HIV/AIDS or cardiac conditions, lung disease, cirrhosis. And in our home State of Indiana, sadly, we have seen an incredibly growing number of Hepatitis C cases linked to the injection drug use occurring in tandem with the opioid crisis.

And so I am interested in each of your perspectives, wouldn't you agree that care coordination, which we have heard a little bit about and which I think Dr. Bucshon was just talking about, is absolutely vital to ensuring better outcomes for those patients with chronic conditions, and in many ways, wouldn't you consider substance use disorder a chronic condition as well? Sir?

Mr. McKee. Congresswoman, thank you for that. Care coordination is at the heart of better health outcomes. It has allowed us in Ohio to make significant advances and moving away from volume and towards value.

If we don't have care coordination -- you know, part of the reason the mental health system is so broken, especially for the chronically mentally ill, is because we don't have enough care coordination. We are working on that in Ohio. This is simply another step in that direction.

Mrs. Brooks. And don't we know that those with serious mental illness also often don't have their chronic conditions taken care of,

their cooccurring conditions; they have worse other health outcomes?

Mr. McKee. Congresswoman, that is absolutely correct. And I would love for you to join as a member of NAMI in Indiana.

Mrs. Brooks. Thank you. Yes, Ms. Metcalf.

Can you hit your mike, please? Thank you.

Ms. Metcalf. Absolutely, we agree that care coordination is critical. We 100 percent support that, not at the expense of taking away our right to choose who our information goes to.

Mrs. Brooks. Except that we visit often, and I just visited when I was back home in Indiana last week ER physicians at Eskenazi Health. And when people are coming in overdosing, and we have hospitals saving lives each and every day, but those individuals have no ability to share any information about what their condition is.

And so why would we want to tie the hands, particularly of those in our ERs, that are being inundated with people overdosing? Why would we not want them to have access to know what is happening in that individual's life?

Mr. Gardner?

Mr. Gardner. I was just going to say that addiction treatment is changing pretty drastically in recent years. We are really making an attempt to keep people engaged in care longer. It is no longer you come to a building and you are there for 28 days and you go home.

Mrs. Brooks. Sure. Outpatient, everything.

Mr. Gardner. You may go from residential to outpatient. You may go back to your home community. And we are facilitating that ongoing care more and more. Partly, that has been driven by the fact that more and more medication-assisted treatment is taking place, including at our facilities. But you need to link people with prescribers in their home communities and ongoing therapy for this to work. So care coordination like never before has become important in addiction treatment.

Mrs. Brooks. Dr. Clark, and I want time for Mr. DeLoss.

Dr. Clark. Care coordination requires patient cooperation, patient compliance. It is not just the prescriber's role.

Mrs. Brooks. Excuse me. But what if the patient has OD'd?

Dr. Clark. Well, oddly enough, the emergency room doctor is not controlled by 42 CFR part 2, and we can enhance that. So we also are dealing with heroin and Fentanyl.

Mrs. Brooks. But how would the ER physician get access to that individual's substance addiction history?

Dr. Clark. This bill won't change that. What we are trying to do is encourage people, as Mr. Gardner said, if we can intervene early enough, we don't deal with this. One of the things with medication-assisted treatment is the average length of stay is only

6 months. And so what we are trying to do is trying to foster that longer period of time so that we can facilitate recovery. And that is what SAVR is about, trying to get people to recognize that they remain vulnerable and, just as was previously mentioned, just a small amount of fentanyl, a small amount of heroin --

Mrs. Brooks. Thank you, sir. I would like to hear from the last panelist.

Mr. DeLoss, would this bill help ensure that an ER physician could get access to a substance abuse record?

Mr. DeLoss. Absolutely. An ER physician is a covered entity and would receive the information under the TPO exemption that is in this bill. So the ER physician would receive all of the information available relevant to the SUD treatment, relevant to the overdose, and be able to treat that condition and the overdose more effectively.

If I could continue, I would also like to expand on there has been a lot of discussion with respect to other providers in the community trying to coordinate care and provide treatment services or their own medical-surgical services. I would like to speak on behalf of the SUD programs. They want the information from those other providers as well. They want to partner with the physicians. They want to partner with the hospitals, but they can't because of part 2, because it is too complex, it is overly stringent. That information not only cannot

be disclosed by the program, but the program can't go out and ask for that information, because that information would identify the patient as suffering from an SUD. So they are not able to coordinate the care as well.

There is a number of other issues -- and I will stop there unless there are other questions.

Mrs. Brooks. Well, and I think that, on behalf of patients in Indiana, the SUD programs do need to coordinate, particularly with the infectious disease conditions that we are seeing an incredible rise in Indiana.

Thank you, I yield back.

Mr. Burgess. The chair thanks the gentlelady. The gentlelady yields back.

The chair recognizes the gentleman from Virginia, Mr. Griffith, the vice chairman of the Oversight and Investigations Subcommittee, 5 minutes for your questions, please.

Mr. Griffith. Thank you very much, Mr. Chairman, I appreciate it. This is one of those difficult issues, and I appreciate you, Mr. Chairman, holding this hearing, because I am trying to figure out exactly what I should do and how I should go on this. And I was not decided coming in here. I leaned towards voting for the bill, because we have had problems for some time. I also have concerns on the privacy

side.

So let me go over some of those issues that we have. You know, as early as -- or last year, we had Brian Moran, the Secretary of Homeland Security and Public Safety from Virginia in. He said, "We got to do something, and it would help us to combat the opioid epidemic and save lives if we could have improved data sharing," and he specifically mentioned part 2.

And I do think, and Mr. McKee, if I could ask a couple questions of your situation and I know it is painful and I appreciate you being here today to discuss it. Your brother was doing well when he had the accident. Is that correct? Is that my understanding?

Mr. McKee. He had had periods of sobriety and periods of relapse, and I am not sure how many relapses and how close together they were.

Mr. Griffith. Okay. Fair enough, because he didn't tell you everything. And then he has this accident. And as a part of the accident, they had to do surgery. Was that surgery something that they did immediately upon him having the accident?

Mr. McKee. It was not immediate. He was stabilized in Worcester Community Hospital, and then he was driven to Cleveland Metro Hospital.

Mr. Griffith. So here is the question I have, and you may not know the answer. When he stabilized, did they give him opioids for the pain that he was experiencing at that time?

Mr. McKee. Absolutely.

Mr. Griffith. And he was not fully conscious, was he?

Mr. McKee. No. He was making some jokes about the appearance of the nurse when I came to see him.

Mr. Griffith. Okay. So here is what is interesting, and I have this theory. Documentary archeology, you can sometimes go into documents and figure out that people didn't realize what the future would hold. This bill was passed in the early seventies. And what you find in the bill is you have got a section on medical emergencies. Under the procedures required by paragraph C of this section, patient identifying information may be disclosed to medical personnel to the extent necessary to meet a bona fide medical emergency in which the patient's prior informed consent cannot be obtained.

Your brother couldn't give informed consent. Forget his abuse problems; he has just been in an accident. They were probably giving him opioids -- and you suspect that and I do too -- before he ever gets sent over for the surgery, before he ever gets the prescription. And because of the way the law is written, or at least as it has been interpreted for the last 40 years, nobody knows that he has a substance abuse problem. So they have already given him substances before he ever has a chance to waive. So I recognize that. You see that problem as well, don't you, yes or no?

Mr. McKee. Yes, Congressman.

Mr. Griffith. Okay, because I am just trying to get to the other side. Now, here is the other side of this. I have got this hypothetical forming in my head where the person who has previously had a substance abuse problem goes to apply for a job, and that job happens to be a covered entity who has access to all this information. And maybe they are not supposed to use it that way, but they have access to all this information. And let's just assume that this person happens to be a medical professional, let's say a nurse, for the sake of argument. And they are going to go to work for, say, an insurance company, working for the insurance company, who is going to provide the health insurance, because that is what they do.

What is the likelihood that, notwithstanding the fact that you are never going to see the fingerprints, Ms. Metcalf, what is the likelihood that that nurse is never going to get that job, that he is going to be excluded, because as they are doing the work-up on the paperwork and so forth, they discover that he has got a prior substance abuse problem. And they will never say why, but all of a sudden, oh, we found out we don't have an opening. What do you think those odds are?

Ms. Metcalf. It is a very tight job market out there. Of course, they are going to go with someone that does not have a history of a

substance abuse disorder. That is the history of discrimination.

Mr. Griffith. And my colleague says, why would they do that? And, of course, maybe they would; maybe they wouldn't. I don't know. But this is the concern that people with substance abuse problems in their past, and they are on recovery, they are doing well; they worry about these things.

So, Dr. Clark, as my lawyer doctor on this team, here is what we need help on. There are some of us that want to find a balance, because without something as an alternative, I am voting for the bill. That is what I have assessed today, because there is more good than evil. And even though I worry about the privacy concerns and agree with Mr. Barton and others, I don't have an alternative. Now, we got to fix HIPAA at some point too. That is a whole other discussion, Mr. Chairman.

But, right now, I have got a lot of people -- nobody anticipated in the early seventies that we would have drugs so powerful that you would be addicted. Six percent we heard earlier somewhere in the studies I have been doing the last week or so, 6 percent on a first use of certain opioids are addicted, 13 percent if you extend that out over a period of time. You know, we are dealing with a whole lot more dangerous drugs than we knew about when this bill was passed. So I am going to vote for this unless I have an alternative.

I don't have any time left. But if you can get me any answers, any advice on how we might be able to make this bill better or an alternative, I would greatly appreciate it. Thank you for you all listening and for your input today, and it has been very educational for a guy who was undecided walking in here.

I yield back.

Mr. Burgess. The chair thanks the gentleman.

I do want to point out to Dr. Bucshon those dietary supplements, they are all natural so it is okay. It is okay, right? They are all natural.

Mr. Bucshon. They thin your blood.

Mr. Burgess. I am going to ask the indulgence of Mr. Mullin. I know he is anxious to yield to me for my questions, but could we go to Mr. Carter and hear from him?

Mr. Carter, you are recognized for 5 minutes, please.

Mr. Carter. Thank you, Mr. Chairman.

And thank all of you for being here. And thank you especially for your personal stories. They have been very inspirational.

And, Mr. McKee, I will start with you. I really do appreciate your stories and especially appreciate your work with NAMI. What a great group. I worked with them when I was in the State legislature, and I continue to work with them here, and they truly do some great

work, and I appreciate that.

I wanted to ask you, from your perspective, after all you have been through, integrated care can change a patient's trajectory. Do you believe that?

Mr. McKee. Absolutely.

Mr. Carter. And, obviously, you have given an example where you thought in your particular situation where it could have. I am a pharmacist professionally, and I practiced pharmacy for over 30 years, and I have been wringing my mind in trying to think how I can incorporate my experiences into this.

And, you know, having tools in our toolbox is very important, and I am just thinking along the lines that if I had the opportunity to know that someone had a history of substance use disorder, that that would help me in my practice. It would help me help my patients. And that is what pharmacists want to do, they want to serve their patients and help them.

And I am just thinking, I am just trying to figure out what would be the downside of this? I mean, you know, I have had the opportunity to be at a number of different conferences and to speak on substance abuse. In fact, one of those conferences was down in Atlanta, the Prescription Drug Abuse and Heroin Conference that Representative Hal Rogers sponsors every year. And I have had an opportunity. And one

of the things we talked about at that conference is the stigma, and that is a big problem we have to get over, particularly when we are talking about the opioid addiction. You know, I suspect and one of the things we talked about at that conference in particular was that we say there are 115 people dying every day because of opioid abuse or opioid addiction. It is probably a lot higher than that. You look at obituaries in papers, and you will see it was a sudden illness, or it was even suicide. And there are families and individuals who would rather say that it was a sudden illness or a suicide than to say it was substance use disorder.

And just, you know, if I could go to Mr. Gardner and just ask you, I know you mentioned earlier about all these forms you had to fill out and the sense that it just stigmatized you, made you feel -- can you just elaborate on that, what your feelings were with that?

Mr. Gardner. Well, when I went to treatment myself 12 years ago, before I went -- and I am just one person so, again, I am not speaking for all patients. But I called my boss. I called three or four people that I figured needed to know before I went. I wasn't sure how I could keep that secret in the first place, to be quite honest with you.

And I had no assumption necessarily. Of course, I had some, you know, embarrassment or shame or frustration mainly about why I couldn't get this under control myself, but I didn't have an assumption that

I needed to keep getting healthy or better or getting help a secret. I really truly genuinely believed that that notion was introduced to me in some way by the consent process.

Mr. Carter. Right.

Mr. Gardner. Well, not just the consent process. See, I don't want to oversimplify it. Stigma is a much bigger, broader thing. And I just think this overall paradigm of secrecy and separation, separating this particular illness from the rest of healthcare over time is stigmatizing.

I mean, I think the healthcare -- can I say one more thing?

Mr. Carter. Sure.

Mr. Gardner. The healthcare industry is one of the places where this has been neglected the most in the past. And so I think things are changing for the better. Healthcare is at the table now, really -- I mean, you know here in this -- in the halls of Congress how much attitudes have changed drastically in the last 5 years, 10 years, and in healthcare.

So, for example, I think if we want to have, as I do, substance use curriculum in medical schools as a part of becoming a doctor --

Mr. Carter. Absolutely.

Mr. Gardner. -- which I think is paramount, I think we need to open these highways to integration and get --

Mr. Carter. So, in other words, it is time to pull the drapes back. It is time to open it up. And, you know, I am not just talking about patients. It is time for us as a society to recognize -- and then we talked about NAMI. It is time for us to recognize that these are truly diseases here. You know, this is not something someone chooses in a lot of cases. This is something that needs medical treatment.

I have not, during this testimony today, found one reason why I don't support this legislation. I have just simply not. I want to thank the author of the bill for bringing this forward. This is something -- you know, it is time for us to get through the seventies and get into 2018. So thank you for bringing this forward. And thank all of you again for being here and for your testimony and your work.

I yield back, Mr. Chairman.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair is prepared to recognize Mr. Mullin if Mr. Mullin will yield to the chair.

Mr. Mullin. I would yield my time gladly to Mr. Chairman.

Mr. Burgess. Thank you for that.

And as far as the seventies are concerned, Dr. Clark, you and I are probably about the same vintage in our medical school training.

42 CFR, a product of the seventies. I actually did take during my time in medical school, I was actually partitioned out to a methadone clinic that was state of the art in 1974 for substance abuse treatment. Unfortunately, it is still state of the art, and I don't know that it has improved a great deal, which is the thing that concerns me about our continuation down the path with 42 CFR, a 1972 law. It seems to be an obstacle of prevention from us modernizing our system.

And several people have referenced the panel of family members that we had here a couple of weeks ago. And it was tough, it was a tough afternoon, tough morning listening to their stories.

I appreciate, Dr. Clark, that you say that there are emergency provisions, but I am sorry: I practiced for 25 years. I am not sure that I knew that.

And we had a young woman tell us about a problem she had had in her family, and she talked about her son, and he suffered a fatal overdose and his fatal overdose April 20th of 2016. He had been seen at the hospital and revived with NARCAN seven times over the previous year. Her words, seven missed opportunities to intervene and save this young man's life.

Okay, there was an emergency provision that they perhaps could have disclosed the data, but it doesn't do Emmitt any good, does it?

Dr. Clark. But 42 CFR part 2 nor HIPAA were relevant to that

situation.

Mr. Burgess. Here is the problem, Dr. Clark, and I am sympathetic with a lot of the points you bring up, but we have created so much confusion that the practitioners don't even -- the doctors don't even know.

Okay, a high-profile case, a young man flying on his Learjet from one point to another, got some bad Vicodin that caused his respiratory depression. They landed his plane. And it took two doses of NARCAN to bring him back around. And now the emergency room doctor is being sued for not picking up on the fact that two doses of NARCAN was an unusual amount to require. And this individual, according to news reports -- I am not mentioning the name on purpose, but according to news reports, refused a tox screen.

I mean, we have got to open up and talk to each other. The siloing of this stuff is what is killing people, in my opinion. And, again, I am just a simple country doctor. But hearing these, story after story after story, we have got to do better than what we are doing.

Mr. DeLoss, I wanted to give you an opportunity to talk about this a little bit. I know that you said, with 42 CFR -- of course, 42 CFR, there weren't data breaches, right? Or if there were, we didn't know what they were. We used to call it theft back then.

So there is no protection or duty to inform about a data -- there

is no data breach notification requirement in 42 CFR, but there would be under the Mullin bill. Is that correct?

Mr. DeLoss. That is correct. There has been historically no breach notification provisions. And the bill does require that.

Mr. Burgess. So the people who are really, really spun up about privacy, there is actually more protection in what Mr. Mullin has proposed to us than what exists under the 1972 law.

Mr. DeLoss. Agreed, yes.

Mr. Burgess. Dr. Clark, since you are here and you are a doctor and a lawyer, let me ask you -- and, of course, you are never supposed to ask a question you don't know the answer to. And I don't know the answer to it, so I am going to ask you.

Current law -- Mr. Griffith kind of alluded to it a little bit. I think the situation that he described where an employer is a covered entity, I think that would be running afoul of the law, but just in general, is someone who is in recovery, is that information information that has to be disclosed to an employer, or may it be withheld from an employer?

Dr. Clark. If they are truly in recovery under the ADA, they can't use it. On the other hand, if the employer has the information, they just don't have to announce it. So, if an employer knows something, they don't have to acknowledge it. They simply penalize

the applicant for other reasons.

Mr. Burgess. So, if they are on medication-assisted therapy, they are going to have a chemical, positive chemical test, a urinalysis. Is that correct?

Dr. Clark. Unless they are under DOT. For instance, if you are on methadone, under DOT, you can't get a safety-sensitive position.

Mr. Burgess. You can't get what, I am sorry?

Dr. Clark. Safety sensitive. You can't be a driver of commercial -- you can't get a commercial driver's license on methadone. That is not true for people on NARCAN, but those are the kinds of arcane rules that people have to live with.

Mr. Burgess. But if you wanted to go work in a department store, that information may not be disclosed to the HR personnel at the department store?

Dr. Clark. It wouldn't have to be.

Mr. Burgess. Yet, at the same time, if there were something that happened that resulted in liability on the part of the department store owner, would all of that information be discoverable? Again, I am not a lawyer.

Dr. Clark. It would be discoverable subsequently.

Mr. Burgess. It would be discoverable?

Dr. Clark. Depending upon court orders. All information, once

it is subject to a court order, including under HIPAA, they would be able to reach it.

Mr. Burgess. So who bears the liability? Does the department store owner then, who couldn't get the information, are they --

Dr. Clark. That would be subject to the litigation. And that is exactly --

Mr. Burgess. And I realize that is far afield. That is not part of the Mullin bill, but it is a question I have had for some time.

Dr. Clark. It is an important question, sir.

Mr. Burgess. I need to recognize Mr. Engel for 5 minutes for questions.

Mr. Engel. Thank you, Mr. Chairman and Mr. Ranking Member Green.

During our subcommittee's April 12th hearing, I asked Michael Botticelli about H.R. 3545. Mr. Botticelli is currently the executive director of the Grayken Center for Addiction at Boston Medical Center and served as the director of the Office of National Drug Control Policy.

When I asked if he had concerns about altering the protections provided by 42 CFR part 2, Mr. Botticelli said, and I quote: "I do, both as a policymaker and as a person in long-term recovery." He went on to say: "Unfortunately, substance use disorders are different from other diseases," unquote.

We know that Americans living with substance abuse disorders face stigma and discrimination that people living with other diseases do not, and we know that, as a result, those Americans might be hesitant to seek what could be the lifesaving treatment for fear of discrimination that remains pervasive.

It is our responsibility to ensure that our actions do not make this problem worse, and that is why today's discussion is so important. And I thank all the witnesses for being here and for sharing your insights.

Let me ask Ms. McCarthy Metcalf, I was here before when you gave your testimony and thank you for sharing your story with us. You noted in your testimony that you do regularly encounter medical providers who do not understand the 42 CFR part 2 protections and mistakenly believe it to be a barrier to care because they do not understand how 42 CFR part 2 works or the recent changes made to them. So they work in our 21st century healthcare environment. That is what you said.

Could you please describe the sorts of questions you typically get from providers about 42 CFR part 2 and what kinds of misunderstandings have you seen?

Ms. Metcalf. From what we have heard that has been reported to us, providers, medical providers don't understand the rule changing or the updates to the rules. So there is a lot of education that is

now being done that SAMHSA is rolling out, and we haven't given that enough time, enough chance to educate medical providers or the community to understand how the new rules fit in with the new healthcare system.

Mr. Engel. Let me ask you this: Given what you have said in your testimony, do you believe better provider education would mitigate the perception that 42 CFR part 2 creates barriers to care?

Ms. Metcalf. Yes. Greater provider education will help to -- you know, would work to support 42 CFR to protect the patient.

Mr. Engel. Let me ask you this, and let me ask -- well, let me ask you this: We have heard that requiring patient consent to disclose their treatment records is problematic because it is argued patients won't do something that could keep them from getting certain substances. Could you respond to that argument?

Mr. DeLoss. I am sorry; I didn't understand.

Mr. Engel. That requiring patient consent before disclosing treatment records is problematic because it is argued patients won't do something that could keep them from getting certain substances.

Ms. Metcalf. I mean, it may be hard to get consent to share information about previous substance use treatment, but that is part of that process when they engage in treatment, and that is what the counseling -- when they are able to provide that. It is encouraged

that they provide that so that they can share that information with their doctors.

Mr. Engel. Dr. Clark, can I ask you that question too? I will repeat it. We have heard that requiring patient consent to disclose their treatment records is problematic because it is argued that patients won't do something that could keep them from getting certain substances.

Dr. Clark. I don't think that is the case. By the time people present to treatment, they have had a number of problems associated in their lives, either with family, with employment, with housing, with the law, and as a result, even if they are ambivalent about treatment, they will be engaged. And it is incumbent upon the professionals to help facilitate that.

You have to keep into consideration that the delivery system is more of a cottage industry delivery system, despite the fact that people are trying to commercialize it. And as a result, it is the lack of electronic health information for the substance use disorder delivery system that keeps information from being shared rather than the patient not being able to share that information.

Mr. Engel. Thank you. My time is up.

Thank you, Mr. Chairman.

Mr. Burgess. The chair thanks the gentleman.

The chair recognizes the gentleman from Florida 5 minutes for questions.

Mr. Bilirakis. Thank you, Mr. Chairman. I appreciate it.

First question for Mr. Gardner and Mr. McKee. In your opinion from your own experiences, do you think the legislation we are reviewing today will discourage people from seeking substance use disorder treatment? First, Mr. Gardner, please.

Mr. Gardner. Thank you for the question, Congressman. I do not believe that it will discourage people from help seeking.

Mr. Bilirakis. That is so important.

Mr. McKee?

Mr. McKee. I do not think that it will discourage people from seeking treatment. I think that there are a number of factors that motivate people to move towards treatment. And if they truly are in a phase for action, confidentiality is not necessarily something that is going to keep them from getting the treatment that they want.

Mr. Bilirakis. Very good. I agree.

Again, for both of you, could patients in SUD treatment today be referred to a primary care physician who is unable to view the patient's diagnosis due to 42 CFR part 2 and be unknowingly prescribed opioids? Mr. Gardner?

Mr. Gardner. Is it possible to be referred?

Mr. Bilirakis. Under the current law, yes.

Mr. Gardner. To be referred by the SUD provider to a primary care provider without consent?

Mr. Bilirakis. Yes. So, in other words -- well, so the primary care doctor would prescribe the opioid, not knowing that this person may have a substance abuse issue. You see what I am getting at?

Mr. Gardner. I think so, yes. That is definitely possible, yes.

Mr. Bilirakis. And we are trying to prevent that from happening with this legislation.

All right, sir, can you answer that question, please?

Mr. McKee. Congressman, yes. In the case of my brother, the orthopedist did not have the luxury of a substance use counselor or a psychiatrist in order to build rapport to move them through precontemplation, contemplation, preparation, and action stages that are associated with addiction. They had to give him aftercare. There wasn't time to wait. And they gave a loaded gun to a person who is suicidal.

You are giving opiates to an addict. And there was no time for him to build that rapport in order to get that consent. Bill.

Mr. Burgess. Would the gentleman yield on that, please?

Mr. Bilirakis. Yes, please.

Mr. Burgess. Just, Mr. McKee, further observation, in the way

things have evolved, now you are not even being discharged from the hospital by your orthopedist. It is a hospitalist who probably has never seen you before. And that is an unfortunate derivation.

I mean, I am not aware of when your brother was injured, but current practice is the orthopedist, in fact, would then delegate care to the hospitalist, who would be in charge of the posthospital care.

Mr. McKee. Thank you for that clarification. And that just underscores the need for better care coordination, which requires some transparency under the protections of HIPAA law.

Mr. Burgess. Thank you.

Mr. Bilirakis. So the next question for Mr. DeLoss. The VA has sorted out a system for gathering a patient's consent to share their full health record across providers, and that benefits the administration for filing claims. They have established a system where the VA consent form is valid for 12 months. And if protocols are followed, the entire record can be shared. This aligns much more closely with HIPAA than current practices for nonveterans.

In your opinion, are veterans suffering from this policy? And I happen to be the vice chairman of the Veterans Committee, so I am familiar with this. So, in your opinion, are veterans suffering from this policy, if you are familiar with the VA?

Mr. DeLoss. I am not very familiar with the veteran system, but

with respect to having additional information to treat the veteran, I would assume that yes, they would be treated much better.

Mr. Bilirakis. Okay. Okay. So do you know if we have seen disproportionally fewer veterans seeking treatment as a result of this policy?

Mr. DeLoss. I am not familiar.

Mr. Bilirakis. You are not as familiar. Anyone else want to answer that question -- who is familiar with the VA, with the system?

Dr. Clark. I am familiar with the VA. I spent 14 years as an addiction psychiatrist in the VA working with PTSD and other conditions. And the fact of the matter is, clearly, they are better off if there is more information being shared. I won't argue with that at all.

So, with the VA establishing working relationships, because the VA has had her issues in the past establishing relationships with external entities sharing that information, but the receiving entity and the VA, if you are going to use the electronic health record, has to be interoperable. And I can tell you interoperability continues to be a problem.

So often the record is not read because whether the hospitalist has time to read it or not. My mother was just in the hospital, and she went from a skilled nursing facility to the same system. They

hadn't read the records.

So we need to be careful about these panaceas, assuming things that will happen that, in practice, actually don't happen. But, if you have got interoperability and you have got a working relationship, you can enhance the care, preferably with the veteran's okay because then the patient doesn't show up if the system is seen as hostile.

Mr. Bilirakis. In this case, we get the veteran's consent. So, if it works like it should work, then I think that it is in the best interests of the veteran.

Thank you very much, and I yield back, Doctor.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

I do want to thank our panel. Seeing no further members who wish to ask questions. Again, we really do owe you a debt of gratitude for being here today and staying with us for so long. There you have it, we are going to have a vote on the floor so we finished right in the nick of time.

I have a lengthy list of statements in support of the Mullin bill that I would like to submit for the record: The Kennedy Forum; Magellan Health; Healthcare Leadership Council; United States Department of Health and Human Services Substance Abuse and Mental Health Administration; America's Essential Hospitals; American Society of

Addiction Medicine; National Association of State Mental Health Program Directors; the American Association on Health and Disability; National Alliance on Mental Illness; the American Hospital Association; the Academy of Managed Care Pharmacy; Avera; OCHIN; Pharmaceutical Care Management Association; Shatterproof; Trinity Health; Association for Behavioral Health and Wellness; Mental Health America; the National Association of Medicaid Directors; Oregon Association of Hospitals and Health Systems; American Health Information Management Association; Blue Cross Blue Shield Association; Association for Community Affiliated Plans; Hazelden Betty Ford; Centerstone; Premier Healthcare Alliance; Catholic Health Association; Information Management; College of Healthcare Information Management Executives; Partnership to Amend Part 2; Confidentiality Coalition; the House of Representatives Rural Relief Initiative; Port Gamble Tribe; American Psychiatric Association; America's Health Insurance Plans; National Association of Accountable Care Organizations; and a joint statement from the National Association of ACOs, Premier, and the American Medical Group Association.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Burgess. Additionally, Mr. Green had asked unanimous consent for the following letters expressing opposition to H.R. 3545 be in the record. This includes the National Advocates for Pregnant Women; the National Association for Children of Addiction; Opioid Treatment Association of Rhode Island; Ringgold Treatment Center; Victory Clinical Services; Recovery Network of Programs; SC Association for the Treatment of Opioid Dependence; Northern Parkway Treatment Services Incorporated; BH Health Services; Serenity Health; Kentucky Mental Health Coalition; President of the Kentucky Association for the Treatment of Opioid Dependence; People Advocating Recovery; Long Island Recovery Association; Faces & Voices of Recovery; Pennsylvania Recovery Organizations Alliance; Campaign to Protect Part 2; National Council on Alcoholism and Drug Dependence of San Fernando Valley; Opioid Treatment Providers of Georgia; Mid-Michigan Recovery Services; Southwest Carolina Treatment Center; Futures Without Violence; Sally Carr, parent of a son with addiction and representative of Never Surrender Hope; Lauren Wicks, National Independent Family Recovery Advocate; National Association for Children of Addiction; Amy E. Sechrist, addiction educator; Randy Flood, recovery coach, Recovery Coaching Services.

[The information follows:]

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

******** COMMITTEE INSERT ********

Mr. Burgess. Pursuant to committee rules, I remind members they have 10 business days to submit additional questions for the record. I ask witnesses to submit the responses within 10 business days upon receipt of those questions.

Without objection, the subcommittee stands adjourned.

[Whereupon, at 4:25 p.m., the subcommittee was adjourned.]