March 20th, 2018

The Honorable Chairman Greg Walden,
The Honorable Ranking Member Frank Pallone
House Energy & Commerce Committee
2125 Rayburn House Office Building
Washington, D.C. 20515

RE: Hearing on Combatting the Opioid Crisis: Prevention and Public Health Strategies - Amendment to HR 3545 the Overdose Prevention and Patient Safety Act"

The Honorable Chairman Walden & Ranking Member Pallone,

Thank you for the opportunity to comment on the proposed Amendment to HR 3545, "the Overdose Prevention and Patient Safety Act." The agency I represent is the Pennsylvania Recovery Organizations – Alliance (PRO-A), the statewide recovery community organization of Pennsylvania founded in 1998. We represent thousands of recovering persons across the state of Pennsylvania. We are dedicated to ending stigma, providing public education about addiction, providing recovery opportunities and to expand access to drug and alcohol services.

We continue to believe strongly that the existing federal confidentiality requirements for substance use conditions information established in 42 U.S.C. § 290dd-2 and 42 CFR Part 2 ("Part 2"), as recently amended twice by SAMHSA, do not require further modifications that would diminish our patient privacy protections in order to achieve the important goal of facilitating the provision of integrated care between substance use disorder information and overall health care.

We remain very concerned that applying the HIPAA Privacy Rule ("HIPAA") standard of allowing without our consent disclosures of our substance use condition records for treatment, payment, health operations or any purpose other than those currently enumerated in Part 2 will result in discrimination against and harm to people living with substance use conditions. The result will be to discourage individuals from seeking SUD treatment even as our number one goal needs to be to encouraging millions more Americans to enter treatment during the worst opioid epidemic in our nation's history.

Section (C) (2) on page 4 of the amendment in the section titled "Use of Records in Criminal, Civil, or Administrative Investigations, Actions or Procedures" identifies a threshold of "absent good cause" for ruling out the use of our information in Criminal, Civil, or Administrative Investigations. This is an ambiguous standard at best and provides insufficient guidance. This will inevitably result in our own information disclosed by seeking help with a substance use condition to be used against us. This will have a chilling impact on the ability of our community to seek help without fear of prosecution.

The Amendment would allow broad access to highly sensitive and personal information. It would be opened up to a vast array of individuals and entities well beyond the counselor treating the person in need and the immediate care provider who need it and can access it under current regulation with our consent.

Additionally, as this information "flows out" to business associates and contracted entities, control over what happens to it decreases while the likelihood of the information being misused or stolen through a breach increases. In instances in which a person has had their information used in a way that caused harm to them, it will become virtually impossible for the patient to determine who was responsible for improperly releasing their information. It is the proverbial wall with a gate open and a pot of gold within.

Our information is that proverbial "pot of gold" and we are deeply concerned about broad dispersal of highly sensitive and personal drug and alcohol related information proposed by the amendment and the lack of clear accountability to us, the patients. It will create conditions favorable to those who would use our information to discriminate against us in a myriad of ways. This includes employment, housing, education and insurance coverage. We have faced the constant drumbeat of the weakening of our protections by business related groups who are perpetually advocating for further weakening and / or elimination of this critically important rule. If one does a google search on medications like "Narcan" or "Buprenorphine" coupled with the term "Life Insurance" one will find how information available within patient records are being used to deny life insurance to people. Turning on the news this week, one is confronted with how Cambridge Analytica used a research clause to gain information on people to use as Kompromat. Drug and Alcohol patient records would be a primary target of other such groups working to gain access to our highly sensitive information. Treatment will become unsafe to participate in.

The sad reality is that there are compelling reasons for entities to obtain and use this information to discriminate against us for their own material gain. 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, in most cases individuals would not do so as by the very act of trying to assert their rights would acknowledge drug addiction in a way that would open them up to prosecution and discrimination. In that sense the Amendment has toothless penalties as due process will be un-obtainable by those so harmed.

The Amendment endangers the fragile therapeutic alliance and may well reduce access to care as who gets our patient information becomes unknowable to the patient. It will be no longer possible for the person in care to determine who gets their information and how it will be used (or misused). Information could now go in a myriad of directions once entered into the medical data base. If the information is used to discriminate against us, it is also nearly impossible from the patient perspective to determine how such a violation occurred and who was responsible.

Under this Amendment, as the treating clinician (I have nearly three decades of direct care experience) I would have to tell my clients that I have no idea who will get their patient information, or how it will be used. I will note that I am a person in long term, continuous recovery for over 31 years. *Under this amendment, I would have not entered treatment or self-edited my disclosures in a way that would have undermined my own care*. Without strict protections, I would not have gotten help, obtained an education and have had the opportunity to be a productive citizen. It is quite possible I would not have survived. This is not just my story, this is true for so very many of us in recovery.

Please understand that there is much greater stigma around substance use conditions than other kinds of medical conditions, and the very acknowledgment of having a substance use condition can open us up to

discrimination and in many instances, place us in legal jeopardy. We will face a Hobson's choice when seeking help under the proposed amendment.

We implore you to not further weaken our confidentiality rights. We are concerned that these proposed changes add many layers of legalese, complexity and ambiguity to the regulations and will serve only to create further confusion. It is worth noting that even with our simpler, current standard many direct care professionals do not understand that they can access all the clinical information they need with a properly executed consent. It is also worth noting that each revision of the standard has made it more complex and harder to understand, which is in and of itself a barrier to care for patients. Others seem to not want to bothered to honor our privacy rights.

We believe that the patient should retain control over who gets this information and how it is used. It is important to note that substance use conditions are almost always fatal without help, that few people can afford to pay out of pocket for care as a direct result of the condition and that treatment at times can be compulsory. The bottom line is that if information that can harm us is widely available, we are left with no real choices beyond avoiding care or risking the use of our information to discriminate against us after it flows to covered entities and beyond based on "absent probable cause" language, business, research allowances and many other ways.

We believe that expanding access to our information opens it up to misuse and urge policymakers to protect us from the misuse of our information and to hold those who use it to discriminate against us accountable to protect our information. This is the standard that Congress strived for back in 1972, which we believe is just as relevant now:

> *"The conferees wish to stress their conviction that the strictest adherence to the provisions of this section is absolutely essential to the success of all drug abuse prevention programs. Every patient and former patient must be assured that his right to privacy will be protected. Without that assurance, fear of public disclosure of drug abuse or of records that will discourage thousands from seeking the treatment they must have if this tragic national problem is to be overcome."*

We staunchly believe that sharing of addiction and recovery information is an individual choice to be made by the individual **who retains control over how it is used and honors the need to limit access to highly sensitive information** – we think that this is fundamental to quality care and consistent with the original statutes and we ask that the original intent be honored.

Respectfully Submitted,

William Stauffer, LSW, CCS, CADC
Executive Director