

# **S U M M A R Y   R E P O R T**

Stakeholder Assessment of Pennsylvania's  
Substance Use Disorder Confidentiality Policies

# **A P P E N D I C E S**



# **A P P E N D I C E S**

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## **A P P E N D I X A :**

Comparison of Pennsylvania and Federal SUD  
Confidentiality

	Regulating Agency	Which entities must comply with these requirements?	What client information is regulated under these requirements?	Are there limits on what information may be shared <u>with</u> a person's consent?	Are there limits on what information may be shared <u>without</u> a person's consent?
<b>Health Insurance Portability and Accountability Act (HIPAA)</b>	<p><b>Federal:</b></p> <p>US Department of Health &amp; Human Services (HHS); Office for Civil Rights (OCR)</p>	<p>Entities covered under the Health Insurance Portability &amp; Accountability Act (HIPAA):</p> <ul style="list-style-type: none"> <li>• Health care providers</li> <li>• Health plans</li> <li>• Healthcare clearinghouses</li> <li>• Business associates</li> </ul>	<p>Protected health information (PHI) includes any information – past, present, or future – about a person's health status, provision of health care, or payment for health care that is created or collected by a Covered Entity (or its Business Associates), &amp; can be linked to a specific individual.</p> <p>This includes information transmitted by electronic media; maintained in electronic media; or transmitted or maintained in any other form or medium.</p>	<p>HIPAA does not limit the purpose for which disclosure may occur with patient consent.</p> <p>See <a href="#">45 CFR 164.502(a)(1)(iii)</a>.</p>	<p>A covered entity is permitted, but not required, to use &amp; disclose PHI, without an individual's authorization, for the following purposes or situations:</p> <ul style="list-style-type: none"> <li>• To the individual</li> <li>• Treatment, payment, &amp; healthcare operations</li> <li>• Uses &amp; disclosures with opportunity to agree or object by asking the individual or giving opportunity to agree or object</li> <li>• Incident to an otherwise permitted use &amp; disclosure</li> <li>• Public interest &amp; benefit activities (e.g., public health activities, victims of abuse or neglect, decedents, research, law enforcement purposes, serious threat to health &amp; safety)</li> <li>• Limited dataset for the purposes of research, public health, or healthcare operations</li> </ul> <p>If a person wants to know how their health information has been shared, they have the right to get a report.</p>
<b>42 CFR Part 2 (Part 2)</b>	<p><b>Federal:</b></p> <p>US Department of Health &amp; Human Services (HHS); Substance Abuse &amp; Mental Health Services Administration (SAMHSA)</p>	<p>Any individual or entity that is:</p> <ul style="list-style-type: none"> <li>• Federally assisted, <u>and</u></li> <li>• Provides SUD diagnosis, treatment or referral for treatment (42 CFR § 2.11).</li> </ul> <p>Most SUD treatment programs are federally assisted in some way.</p>	<p>Information related to identity, diagnosis, prognosis, or treatment of a patient in a federally assisted SUD treatment program.</p>	<p>Part 2 does not limit the purpose for which disclosure may occur with patient consent.</p> <p>Re-disclosure of records (sharing or releasing health information that received from another source and made part of a person's record) is currently prohibited without consent.</p> <p>See <a href="#">42 CFR 2.31</a></p>	<ul style="list-style-type: none"> <li>• Child abuse &amp; neglect report</li> <li>• Cause of death reporting</li> <li>• With valid court order</li> <li>• In case of medical emergency</li> <li>• Reporting crimes on program premises or against staff</li> <li>• To entities with administrative control</li> <li>• To qualified service organizations</li> <li>• To outside auditors, evaluators, central registries, &amp; researchers</li> </ul>

	Regulating Agency	Which entities must comply with these requirements?	What client information is regulated under these requirements?	Are there limits on what information may be shared <u>with</u> a person's consent?	Are there limits on what information may be shared <u>without</u> a person's consent?
<a href="#">PA Act 63 of 1972;</a> <a href="#">71 P.S. § 1690.108</a>	<p><b>State:</b></p> <p>Various</p>	<p>Subsection (b) applies to anyone who prepares or obtains patient records pursuant to this act including private &amp; public SUD treatment &amp; rehabilitative facilities.</p> <p>Subsection (c) includes any provider that holds substance use treatment information &amp; restricts disclosure of any information relating to SUD prepared or obtained by <u>any</u> private healthcare provider or facility</p>	<p>A complete medical, social, occupational, &amp; family history shall be obtained for a person's SUD diagnosis, classification &amp; treatment.</p> <p>Copies of all pertinent records from other agencies, practitioners, institutions, &amp; medical facilities shall be obtained to develop a complete &amp; permanent confidential personal history for purposes of the patient's SUD treatment.</p>	<p>With a patient's consent, SUD information may only be released for the following purposes:</p> <ul style="list-style-type: none"> <li>○ To medical personnel exclusively for diagnosis &amp; treatment;</li> <li>○ To government or other officials for the purpose of obtaining benefits; or</li> <li>○ To the parent or legal guardian of a minor patient</li> </ul>	<ul style="list-style-type: none"> <li>● Life-threatening medical emergencies</li> <li>● Good clause court order, only for providers included under subsection (b)</li> </ul>
<a href="#">4 Pa. Code § 255.5</a> <a href="#">28 Pa. Code § 709.28</a>	<p><b>State:</b></p> <p>Department of Drug &amp; Alcohol Programs (DDAP)</p>	<p>Public or private organizations responsible for the administration &amp; delivery of SUD services as a component of an SCA (i.e., "projects").</p> <p>Other sections of Pennsylvania's Administrative Code incorporate Section 255.5 by reference, extending its application to entities including mental health providers, freestanding SUD treatment facilities, &amp; health care facilities that provide SUD treatment services in inpatient or outpatient settings (such as hospital-based detox). These other entities are required to comply with 255.5 as a condition of licensure or certification. (See <a href="#">28 Pa. Code 711</a>)</p> <p>Part 5 of Title 28 of the Administrative Code contains regulations for DDAP. Chapter 709 contains the standards for licensure of freestanding SUD treatment facilities. Freestanding treatment facilities are those that are not part of a health care facility. (See <a href="#">28 Pa. Code 709</a>)</p>	<p>Client oriented data which reasonably may be utilized to identify the client.</p>	<p>Written consent requires, but is not limited to, 7 elements:</p> <ul style="list-style-type: none"> <li>● Name of individual/organization receiving disclosure;</li> <li>● Specific purpose or need for disclosure;</li> <li>● Description of how much/what info will be disclosed;</li> <li>● Signature of patient;</li> <li>● Date of consent;</li> <li>● Date, event, or condition upon which consent will expire; &amp;</li> <li>● Signature &amp; date of witness.</li> </ul> <p>Even with patient's consent, only 5 pieces of information may be shared with a <i>judge, probation or parole officer, insurance company, health or hospital plan, or government official.</i></p> <ul style="list-style-type: none"> <li>● Whether or not the patient is in treatment;</li> <li>● The prognosis of the patient;</li> <li>● The nature of the project;</li> <li>● A brief description of the patient's progress; &amp;</li> <li>● A short statement as to whether the patient has relapsed into drug or alcohol misuse, &amp; frequency of such relapse.</li> </ul> <p>No limitations on information that a SUD treatment provider can provide to a person's treating <i>physicians.</i></p> <p>See <a href="#">28 Pa. Code 709.28(c)</a></p>	<p>The non-consensual disclosures permitted under 255.5 are:</p> <ul style="list-style-type: none"> <li>● 255.5(a)(1), to sentencing judges when diagnosis or treatment is a condition of sentence - limited by 255.5(b)</li> <li>● 255.5(a)(2), to parole or probation officers when treatment is a condition of probation or parole - limited by 255.5(b)</li> <li>● 255.5(a)(3), to judges when diagnosis or treatment is a condition of presentence or conditional release including ARD, probation without verdict, or disposition in lieu or trial - NOT limited by 255.5(b)</li> <li>● 255.5(a)(9), to medical authorities for the purpose of treating the client in an emergency when the life of the client is in immediate jeopardy - NOT limited by 255.5(b)</li> </ul>

## **A p p e n d i x B :**

### SUD Confidentiality Survey Tool

## CONFIDENTIALITY ATTITUDES AND PRACTICES

### Survey Purpose

The Pennsylvania Department of Drug and Alcohol Programs (DDAP) and the non-profit public health organization Vital Strategies are conducting this survey to understand attitudes and practices related to Pennsylvania's substance use confidentiality statutes and regulations. More information about this project can be found on DDAP's website, [here](#).

Your answers to this survey will help DDAP understand:

- Perceptions of current confidentiality statutes and regulations;
- How Pennsylvania's requirements shape access to services for people who are enrolled in or in need of services for substance use disorder (SUD);
- Current statutes and regulations in the context of our state's public health response to the overdose crisis and national overdose response efforts; and
- The role and effectiveness of current policies in protecting client data, mitigating social harms, addressing stigma, and supporting health and service quality.

Your feedback will help DDAP ensure that the agency's policies are consistently supporting and helping to meet the needs of people living with SUD.

Your replies to this survey will be anonymous. Identifying information (such as your name, address, telephone number, etc.) will not be collected and should not be provided. The data collected in this survey will be used solely for the purposes set out above and will not be used or distributed for future research studies.

Thank you for taking the time to complete this survey.

### Survey Participant Consent Statement

Below are your rights and protections if you decide to proceed as a participant in this survey:

- You can choose not to participate or exit the survey at any time. There is no penalty for not completing the survey.
- This survey is anonymous. No personal identifying information, including IP address, will be collected.
  - Because this survey is anonymous if you exit the survey before finishing the questions you will not be able to save and return to the survey once you exit.
- If you volunteer to participate, you are not giving up any legal claims or rights.
- There is no compensation or incentive for completing this survey. This survey will take approximately 15 minutes to complete online.

This survey is being coordinated by Alex Shirreffs, who is working in DDAP through a partnership with Vital Strategies. You may contact her at 717-736-7486 or [c-ashirref@pa.gov](mailto:c-ashirref@pa.gov) if you have any questions about this survey.

If you have any questions about your rights as survey participant or if you feel that you have been harmed, you may contact Derrick Pelletier, Director of Intergovernmental Affairs, at [dpelletier@pa.gov](mailto:dpelletier@pa.gov).

You may also use the Vital Strategies Reporting Line to raise concerns confidentially or anonymously via 1-800-461-9330 or [www.vitalstrategies.org/report](http://www.vitalstrategies.org/report)

\* 1. Do you agree to take part in the survey?

Yes

No



## CONFIDENTIALITY ATTITUDES AND PRACTICES

### Participant Background

The questions below will help understand the expertise you bring to the subject of SUD confidentiality in Pennsylvania.

\* 2. Which stakeholder group(s) best describe you? (Check all that apply)

- Person with substance use history/lived experience
- Friend or family member of someone with substance use history
- Advocate
- Substance Use Treatment Provider
- Hospital or Health System Administrator
- Health Care Provider
- Behavioral Health Provider
- Government Agency
- Elected Official
- Single County Authority
- Insurance Representative
- Community-Based Organization
- Court Official
- Probation/Parole Officer
- Attorney/Counsel
- Researcher
- Other (please specify)

\* 3. How many years of experience do you have in the drug and alcohol field? *Experience can include your personal lived experience with SUD or professional experience helping and/or treating people with SUD.*



## CONFIDENTIALITY ATTITUDES AND PRACTICES

### Attitudes Towards Pennsylvania's Current Statutes and Regulations

The next set of questions ask you to think about Pennsylvania's current requirements regulating people's SUD records and how they impact your life and/or work. This will help DDAP understand: **How are Pennsylvania's SUD confidentiality states and regulations working now?**

#### SUMMARY OF PENNSYLVANIA'S REQUIREMENTS:

A few different statutes and regulations affect the confidentiality of SUD records in Pennsylvania, primarily:

- The Pennsylvania Drug and Alcohol Abuse and Control Act, also known as Act 1972-63, is the statute that governs the confidentiality of client records prepared or obtained under the Act. It applies to records of SUD treatment prepared or obtained by any SUD or medical provider. See 71 P.S. § 1690.108.
- 4 Pa. Code § 255.5 is a regulation that limits the information and recipients of disclosure of client information by SUD projects and coordinating bodies.
- 28 Pa Code § 709.28 is a regulation that applies confidentiality standards to treatment activities that are licensed under DDAP.

Compliance with Section 255.5 is also written into regulations of mental health and psychiatric treatment providers. See, e.g., 55 Pa. Code § 5100.37.

DDAP has compiled federal and state statutes and regulations into a manual, available [here](#).

#### ANSWER BASED ON YOUR EXPERIENCE & OPINIONS:

Your replies to the questions below will help DDAP understand how Pennsylvania's statutes and regulations impact people with SUD and the stakeholders who serve them.

Think about the benefits and costs of Pennsylvania's current confidentiality statutes and regulations. Your reply will help DDAP understand if there are differences between the intent of these requirements and their implementation on the ground. Please use your observations or experiences from the field to inform your replies.

8. How much do you agree that Pennsylvania's current SUD confidentiality requirements result in the following benefits for clients?

	Disagree Strongly	Disagree	Undecided	Agree	Agree Strongly
They encourage people to seek treatment because they know privacy will be protected	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They keep client in control of own records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They protect client from criminal prosecution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They protect client from adverse actions by employer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They limit data to prevent service denials or reduction of insurance benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They protect client from loss of child custody	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They protect the client from stigma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are no benefits to the current requirements.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. If you have observed other ways Pennsylvania's confidentiality requirements benefit people with SUD, please describe them here.

10. How much do you agree that Pennsylvania's current SUD confidentiality requirements result in the following barriers or challenges for clients?

	Disagree Strongly	Disagree	Undecided	Agree	Agree Strongly
They are too restrictive about which entities can receive data, even with client consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They make it difficult to obtain insurance authorization for treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They prevent expansion of SUD treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They make it difficult to integrate SUD services in health care settings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exclusion of SUD from client records gives providers an incomplete client history	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They make it difficult to evaluate programs and improve services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not fully protect clients from criminal prosecution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not fully prevent negative consequences (e.g. in areas of employment or child custody)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They perpetuate stigma by setting SUD apart from other health conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They do not create any challenges or barriers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. If you have observed other ways Pennsylvania's confidentiality requirements pose challenges that impact people with SUD, please describe them here.

12. In your experience, which specific aspects of Pennsylvania's current SUD confidentiality requirements cause the most challenges for SUD clients or providers? (Select up to three)

- I have not experienced any challenges with the current regulations
- Limitations on the reasons for which disclosure can occur
- Limitations on the entities to whom disclosure can occur
- The level and type of information that can be contained in the disclosure for specific recipients
- Even with their consent, clients are limited in being able to share certain information
- Limitations on access to records for research, evaluation, and quality improvement
- Limitations on data sharing for public health surveillance and program operation
- Other (please specify)

The next question asks you to reflect on whether Pennsylvania needs SUD confidentiality requirements that are more restrictive than the federal standard established by [42 CFR Part 2](#). Most other states align their SUD confidentiality policies with Part 2. Click [here](#) to see how Pennsylvania's regulations compare to other states.

13. Do you think it is necessary for Pennsylvania's SUD confidentiality requirements to be more restrictive than federal regulations?

- Yes
- No
- Neutral or Unsure

Use the space below too elaborate on your position.

14. Use the space below to add any additional thoughts on PA's current SUD confidentiality statutes and regulations.

## CONFIDENTIALITY ATTITUDES AND PRACTICES

### Attitudes Towards Revising Pennsylvania's Statutes and Regulations

The next set of questions ask you to think about ways DDAP can help address challenges with Pennsylvania's SUD confidentiality requirements. This will help DDAP understand: Can Pennsylvania's SUD confidentiality statutes and regulations be improved?

15. Do you think Pennsylvania's current SUD confidentiality statutes and regulations can be improved?

- Yes
- No
- Neutral or Unsure

16. What specific actions would you prefer to be done to improve Pennsylvania's SUD confidentiality requirements? (Select up to three).

- Do not make any changes to the current confidentiality requirements
- Revise requirements to add more SUD confidentiality protections
- Develop guidance materials to clarify requirements
- Revise requirements to account for updates to the field and to make requirements more clear and well-defined
- Revise requirements to align with federal regulations (42 CFR Part 2)

Use the space below to elaborate or provide other options.

In most other states, SUD confidentiality requirements align with federal regulations. If Pennsylvania revised its confidentiality statutes and regulations to do the same...

17. How do you think this might improve the care provided to a person with SUD?

18. How do you think this might challenge the care provided to a person with SUD?

19. Use the space below to add any additional thoughts how you would like to see Pennsylvania's SUD confidentiality statutes and regulations improve.



## CONFIDENTIALITY ATTITUDES AND PRACTICES

**Thank you for completing this survey!**

Thank you for sharing your feedback on this important issue. Project updates will be posted [here](#).

If you have additional thoughts or questions on the issue of SUD confidentiality in Pennsylvania, you can contact the project coordinator, Alex Shirreffs, at 717-736-7486 or [c-ashirref@pa.gov](mailto:c-ashirref@pa.gov).

If you have any questions about your rights as survey participant or if you feel that you have been harmed, you may contact Derrick Pelletier, Director of Intergovernmental Affairs, at [dpelletier@pa.gov](mailto:dpelletier@pa.gov).

You may also use the Vital Strategies Reporting Line to raise concerns confidentially or anonymously via 1-800-461-9330 or [www.vitalstrategies.org/report](http://www.vitalstrategies.org/report).

## **A p p e n d i x C :**

Summary Tables of Free Text Reply Themes

## Appendix C: Summary of Results: Summary tables of free text reply themes

QUESTION 9: If you have observed other ways Pennsylvania's confidentiality requirements <b>benefit</b> people with SUD, please describe them here. (n=215)			
Key Themes	n	Sub-themes Specific to Category	Quotes
<i>57.2% cited benefits and/or expressed support for current requirements (n=123)</i>			
They encourage people to seek treatment because they know privacy will be protected	52	<ul style="list-style-type: none"> <li>• Treatment privacy also impacts mental health treatment</li> <li>• Allows minors to get treatment without parents' consent</li> <li>• Builds trust between a client and their provider</li> <li>• Concern/Fear that changing regs will cause harm</li> <li>• Facilitates holistic/whole person care</li> <li>• Need more education about addiction/SUD</li> <li>• They protect client from criminal prosecution, particularly from immigration officials</li> </ul>	<p><i>The client has a right to privacy in the treatment process. If the participant does not trust that the process is private or confidential, or that he/she will not be penalized for being open in a session, then no real therapeutic interventions may occur.</i></p> <p><i>In those diagnosed with dual issues, it protects all of the issues presented in treatment. What usually is discussed in a treatment setting does not need to go outside of the treatment setting other than to address attendance. Constant reporting of issues erodes the relationship trust that needs to be build in order to get people to open up...</i></p>
General overall protection	16	<ul style="list-style-type: none"> <li>• Treat addiction as disease</li> </ul>	<p><i>SUD helps to protect members private information from being exploited from other entities that has not so good intentions to use members information for their personal gain.</i></p>
Protect client from other entities	15	<ul style="list-style-type: none"> <li>• Other entities named include: <ul style="list-style-type: none"> <li>○ Abusive partners</li> <li>○ Housing</li> <li>○ Life Insurance</li> </ul> </li> <li>• Protect from racial discrimination</li> <li>• Protects from abusive situation</li> </ul>	<p><i>They provide a reasonable balance to ensure that intimate details of peoples personal lives do not end up flowing into and beyond the healthcare systems.</i></p> <p><i>I think it's positive that other medical professionals not see the sub tx record because there is a bias by non-sub tx professionals.</i></p>
Protect the client from multiple entities	9	<ul style="list-style-type: none"> <li>• Clients willing to be open regardless of regs</li> </ul>	<p><i>Working in the field, I've experienced numerous ways requirements protect the patient from information getting to those who may make a decision based on the information that would hurt the patient in the form of stigma or loss of work,</i></p>
They protect the client from stigma	9	<ul style="list-style-type: none"> <li>• Helps reinforce SUD as a disease</li> <li>• Releasing more information could add to stigma</li> </ul>	<p><i>Allotting only the basic data to be released absolutely protects the release of unnecessary information that will only add to irrational stigma and perceptions of those who suffer from SUD.</i></p> <p><i>Drug and Alcohol providers have a higher level of respect for client privacy rights and are more likely to be advocates for clients to protect them from stigma</i></p>

## Appendix C: Summary of Results: Summary tables of free text reply themes

They keep client in control of own records	9	<ul style="list-style-type: none"> <li>Allows client control over their info</li> </ul>	<p><i>The ability to verbally pull consent at any time seems beneficial.</i></p> <p><i>Allows minors to confidentially receive support. Gives agency to clients.</i></p>
Protect the client from criminal prosecution and/or criminal justice entities	8	<ul style="list-style-type: none"> <li>Concern relapse will be addressed punitively instead of allowing for client to get help</li> <li>Discomfort with law enforcement presence in/around treatment setting</li> </ul>	<p><i>Getting individuals to treatment rather than going to jail. We have created a positive relationship with most of the PO's we deal with and once we get an individual to treatment we will call the PO and report that that individual is safe.</i></p> <p><i>I do believe that PA 255.5 helps persons with SUD who are also being monitored by parole or probation to feel that there are safeguards which prevent their parole or probation officer knowing everything that is happening with their treatment. This seems to help clients talk more freely with their treatment staff.</i></p>
They protect client from adverse actions by employer	5		<p><i>The ability to get treatment thru EAP without employer knowing it is for SUDS</i></p> <p><i>If someone has had prior treatment it should not preclude them from being employed, along with if a person is engaged in treatment the employer does not have a right to know</i></p>
<b>14.9% cited benefits but also indicated challenges or room to improve OR response was unclear (n= 32)</b>			
Pros and cons (Some benefits but...)	22	<ul style="list-style-type: none"> <li>Align with mental health regs</li> <li>Do more harm than good</li> <li>Entities that are "blocked" from data by regs are finding other ways to access info</li> <li>Entities that are "blocked" from data by regs are finding other ways to access info - but regs delay them getting it</li> <li>Some benefits but need modification</li> <li>Specific issues in rural areas (familiarity with people)</li> <li>They protect client from loss of child custody</li> </ul>	<p><i>It is important for people to have (and to know they have) privacy in their SUD treatment information and control of how that information is used. Unfortunately the requirements as they currently stand dramatically limit their control of this information and also the ability of community providers and government authorities to effectively plan, implement, and monitor the use of resources to help them.</i></p> <p><i>While the D&amp;A confidentiality may assist in protecting in some ways, because we live in a small community with many crossovers in services, regardless of whether D&amp;A releases information, other social service providers especially, can and do know about clients usage. Often the clients self-disclose or seek copies of their records so that they themselves can share the information they can obtain.</i></p>
Unclear response	10		

## Appendix C: Summary of Results: Summary tables of free text reply themes

27.9% did not cite benefits and/or expressed critique of current requirements (n=60)			
No cited benefit; expressed critique	31	<ul style="list-style-type: none"> <li>• Barrier to SUD treatment</li> <li>• Burdensome</li> <li>• Clients willing to be open regardless of regs</li> <li>• Contributes to racial disparities</li> <li>• Enable the client</li> <li>• Entities that are "blocked" from data by regs hold it against client</li> <li>• False sense of protection</li> <li>• Fosters mistrust between systems</li> <li>• Hinders family engagement</li> <li>• Limits providers trying to help clients</li> <li>• Limits treatment access</li> <li>• Protects people with OUD over ppl they might harm</li> </ul>	<p><i>The fact that treatment is restricted because of the law actually works against this claim... the numbers that indicate access to SUD treatment is poor, and this law contributes to those access issues. I'd argue that the laws actually make it LESS likely someone will seek out treatment.</i></p> <p><i>Team meeting between providers are essential in care coordination. Often times the substance provide is not at the table which inadvertently increases stigma and mistrust. Allow for a comprehensive recovery approach needs to be wholistic.</i></p> <p><i>I don't believe that the average person makes any decision for treatment based on confidentiality. I don't think that the average consumer knows any of the laws and therefor it doesn't have any role to play in their decision. People are thankful for the security but overall are unaware unless they have been to treatment before.</i></p>
There are no benefits to the current requirements	19	<ul style="list-style-type: none"> <li>• Burdensome/Time consuming</li> <li>• Current regs do not actually protect from adverse actions</li> <li>• Federal regulations sufficient</li> <li>• Harms outweigh benefits</li> <li>• Paternalistic</li> </ul>	<p><i>I disagree with most of the touted benefits allegedly attached to current confidentiality regulations. People with SUD continue to experience criminal prosecution, adverse actions from employers, service denials/insurance reductions, loss of child custody, and stigma in spite of our plethora of regulations.</i></p> <p><i>Pennsylvania's law concerning the confidentiality of patient information for persons receiving drug and alcohol treatment is too restrictive, in that it essentially denies the client the ability to share his or her records with whomever he or she chooses.</i></p>
Harms outweigh benefits	10	<ul style="list-style-type: none"> <li>• Some benefits but...</li> </ul>	<p><i>There is no special benefit aside from what general privacy aids with. In fact, the cons far outweigh this, as CLIENTS cannot even consent for things they want to be released and shared, for their safety and integrated care, to be released.</i></p> <p><i>These laws have not been updated for nearly 50 years. While their original intent remains a noble one, we don't live in that world anymore. As much as stigma remains a problem, it is not something that often keeps clients form entering treatment (the ones I see, in any case). What has occurred over time is that these regs have created barriers to a team approach to holistic treatment.</i></p>

## Appendix C: Summary of Results: Summary tables of free text reply themes

QUESTION 11: If you have observed other ways Pennsylvania's confidentiality requirements pose <b>challenges</b> that impact people with SUD, please describe them here. (n=302)			
Key Themes	n	Sub-themes Specific to Category	Sample of Replies
<b>75.8% described challenges with current requirements (n=229)</b>			
Broadly too restrictive	21	<ul style="list-style-type: none"> <li>• Align with federal regulations</li> <li>• Challenge for cross-state care coordination</li> <li>• Confusing</li> <li>• COVID has shown regulations can change quickly</li> <li>• Makes it difficult to obtain insurance authorization</li> <li>• Shields client from interventions ("consequences") that could help them</li> <li>• Supports protection from employer</li> </ul>	<p><i>Stigma exists regardless of confidentiality laws, and those laws in D&amp;A do not allow for as much client freedom of choice as HIPAA, seemingly restricting client-driven services and the integration of care across systems. These regulations as they are also limit crucial communication across treatment providers, case management departments, recovery support departments, and other agencies involved in patient care, where we could be collaborating and involving all voices in assisting the client, especially during crisis.</i></p> <p><i>Empowerment, choice and integration - clients cannot choose to direct their own care or integrate it, which is a barrier to recovery. The silos further perpetuate a 'those people' mentality and impede programs coming together. In addition, this really inhibits engaging supports.</i></p>
Too restrictive about which entities can receive data or what pieces of data can be shared - even with client consent	12	<ul style="list-style-type: none"> <li>• Challenge for providers when entities that are "blocked" from data by regs persist/do not get info they are asking for</li> <li>• Client wants to show progress in treatment (ex: UDS test results)</li> <li>• Impacts ability to help client in court or criminal justice setting</li> <li>• In urgent situation, providers find work arounds to share info regardless of requirements</li> </ul>	<p><i>Clients become frustrated with providers when they recognize that some information cannot be provided even with their consent. They often put the SUD treatment and judicial systems in conflict and in some ways reduce providers ability to advocate fully for their clients within the judicial system. It also can make it difficult to coordinate safety plans with family/significant others.</i></p> <p><i>Clients often don't understand why they can't provide consent for certain information to be released. Especially with Probation officers. They want to demonstrate the good work they are doing but I am not allowed to disclose even with their permission. Another example is employment. Clients ask for specific forms from employers to be filled out that ask for certain information that is not allowed by 255.5. Clients feel comfortable with this information being disclosed to their employer to retain extended time off. However, we are unable to complete it and they lose the time off because the form was not completed even with client permission.</i></p>

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<p>Impede SUD treatment access or continuity of care</p>	<p>30</p>	<ul style="list-style-type: none"> <li>• Added barrier for clients with disabilities</li> <li>• Burdensome/time consuming intake</li> <li>• Difficult to monitor/evaluate programs and improve services</li> <li>• Hard for a clients' other providers to get updates on their SUD treatment</li> <li>• Makes treatment intake challenging</li> <li>• Medical providers penalized for seeking treatment by licensing boards</li> <li>• Not maximizing evidence-based strategies</li> <li>• Prevents low-threshold, expedient access to treatment or services</li> </ul>	<p><i>Gaining consent, while important, also slows the process of gaining treatment when a person with SUD is unable to takes the necessary steps independently. Ex- For example, my family member is hearing impaired. Completing the release of information for me to assist takes valuable time when preventative and treatment services are needed immediately.</i></p> <p><i>PCPs would like to know when their patients have overdose events. They could do outreach if they knew, but this is now not available. Silence from people who are in a position to help after a near-death experience does not make a person feel cared for - but LEGALLY, this is what occurs. Someone who has relapsed or experiences an overdose might feel shame and avoid medical care if they do not know that they will be cared for in an empathic manner.</i></p>
<p>Exclusion of SUD from client records gives care/service providers an incomplete client history</p>	<p>26</p>	<ul style="list-style-type: none"> <li>• Barrier to moving client between levels of care</li> <li>• Federal regulations for methadone also frustrating</li> <li>• Hinders overdose fatality review projects</li> <li>• Would like methadone in PDMP to prevent adverse effects</li> </ul>	<p><i>At times it makes it difficult to coordinate care with members of the physical health plan when we cannot address issues relating to SUD and how it may impact the member. They see gaps of treatment rather than continuity of care.</i></p> <p><i>They prevent fatality review teams from learning about substance use treatment history, which prevents taking action on a systemic level to address systemic shortfalls</i></p>
<p>Limits care coordination/service integration</p>	<p>38</p>	<ul style="list-style-type: none"> <li>• Entities penalized for not coordinating services when clients do not sign off on release of info</li> <li>• Fear of stigma</li> <li>• Limits internal and external coordination</li> <li>• Patients could take advantage of restrictions</li> <li>• Prevents low-threshold, expedient access to treatment or services</li> <li>• Providers find work arounds to share info regardless of requirements</li> <li>• Recommend universal release</li> <li>• SUD exceptionalism</li> <li>• They prevent expansion of SUD treatment</li> </ul>	<p><i>We are a substance use provider operating as part of a larger health system. As a result of having such stringent (and separate) confidentiality requirements, we've had to purchase (at great expense) a completely separate medical record from the rest of our healthcare system. This makes it extremely difficult for us to share/receive information about patients who are presenting with SUDS issues in our ED's and who are transferring into SUDS services from our medical floors. This creates a lot of duplication of effort for both the staff and the patient, creates delays in transitioning the patient and hampers our ability to provide a seamless transition in care.</i></p> <p><i>There are a lot of SUD individuals that are also in need of mental health services, practitioners not having access to SUD information makes the development of effective interventions and treatment for MH difficult if not impossible!</i></p>

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<p>Particular issues related to children, youth and families</p>	<p>19</p>	<ul style="list-style-type: none"> <li>• Challenge to family involvement in treatment process</li> <li>• Confusion about different state regs that intersect - SUD and child welfare</li> <li>• Do not fully prevent negative consequences (e.g. child custody)</li> <li>• Families frustrated when they cannot confirm client is in treatment</li> <li>• Families frustrated when they cannot obtain a loved one's record after they have passed</li> <li>• Hinders communication about a family SUD</li> <li>• Impacts family members affected by SUD but who themselves do not have SUD</li> <li>• Segregating information could put children of parents with SUD at risk</li> <li>• Want show progress in treatment</li> </ul>	<p><i>Without the ability at times to share information appropriately, people (courts, child welfare, POs, family, etc.) often jump to conclusions when there's knowledge someone is in treatment. Additionally, providers are not well versed in Act 126 and what information that allows to be provided to juvenile courts and child welfare. This causes confusion and negative experiences all around.</i></p> <p><i>In terms of providing Multisystemic Therapy services, it is literally impossible to incorporate all key participants in treatment (the D&amp;A counselor/therapist) into treatment. This leaves out crucial information needed, particular with the adolescents we serve, creating a situation where the substance use can not be addressed systemically, which has been proven effective in the adolescent population.</i></p>
<p>They do not fully prevent negative consequences (e.g. in areas of employment or child custody)</p>	<p>13</p>	<ul style="list-style-type: none"> <li>• Harms outweigh benefits</li> <li>• No duty to warn language or involuntary commitment option (like 302)</li> <li>• Prevents intervention in situations where a patient may self-harm</li> <li>• Puts client in a challenging place of needing to account for treatment but being limited in what information can be shared</li> </ul>	<p><i>I have seen clients not be able to obtain housing, jobs, or get their children back in spite of confidentiality requirements</i></p> <p><i>Simple nuances like not being able to specify what substance is in a urine is often far more detrimental to the client than protective, because law enforcement always assumes the worst and discussions around false positive can't take place. Employers aren't to be told whether or not an employee has successfully completed a treatment program, etc... Drug courts are forced to assume the worst in instances where certain details can not be shared in a team staffing. Commercial insurers want more detail, often in an effort to approve a claim than deny it. When we tell them vague answers, generalized answers, etc., it makes the relationship confrontation and less likely to result in approval for initial and ongoing services.</i></p>
<p>They do not fully protect clients from criminal prosecution/impacts ability to help client in court or</p>	<p>29</p>	<ul style="list-style-type: none"> <li>• Hard to get information after consent expires</li> <li>• Client frustrated more information cannot be released</li> <li>• Creates barriers in drug/treatment court</li> <li>• Creates confusion among entities trying to coordinate care/services</li> </ul>	<p><i>People get warrants because treatment can not be verified, because clients did not complete releases for the correct person, or enough detail could not be given regarding the person's presence in treatment.</i></p> <p><i>restrictions on shared information can result in probation/parole violations when PO cannot get enough information from provider to</i></p>



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criminal justice setting		<ul style="list-style-type: none"> <li>• Entities that are not regulated by DDAP (ex: criminal justice) frustrated that their work is impacted by state policies</li> <li>• Exclusion of information can work against a client (and vice versa inclusion of more information could help a client)</li> <li>• If treatment cannot be verified, client could face legal consequences</li> <li>• Knowing what substances a client uses is a safety issue for people working with them</li> <li>• Level of specific detail needed on consent means information might not be released even when client has approved ROI</li> <li>• Limits entities trying to assess whether a person needs help</li> <li>• Post release a vulnerable time for someone with SUD, need to ensure support is in place</li> <li>• Perception that client will not be honest with law enforcement/crim justice entity</li> <li>• Prevents accountability</li> </ul>	<p><i>prove to court that all aspects of court ordered treatment has been completed.</i></p> <p><i>These confidentiality requirements limit what can be said to the courts, the client may have told me something that is impacting their recovery but I can not report it because I am bound by the five points which then results in the client experiencing more struggles and stressors.</i></p> <p><i>Courts often want details of how someone is doing in treatment. When we cannot report specifics, it can be difficult to get across what the client truly needs and, in some cases, explain why a client should not be persecuted</i></p>
They make it difficult to obtain authorization for insurance or other benefits/services	23	<ul style="list-style-type: none"> <li>• Barrier to insurance authorization</li> <li>• Challenge getting SSI benefits approved</li> <li>• Challenge getting time off for treatment approved</li> <li>• Lack of information prevents clients from getting authorization for payment of services</li> <li>• Lack of information prevents clients from getting services that could benefit their treatment or continuity of care</li> </ul>	<p><i>Mainly issues with insurance companies. They are more likely to deny additional services due to the limited information we, as health providers, can provide. Anytime I have ever spoke to clients, they have always said "say whatever they ask for if it will help me continue to get treatment."</i></p> <p><i>They prevent persons from securing needed benefits such as SSI-- particularly in the dual diagnosis populations.</i></p> <p><i>Problems getting FMLA and short-term disability insurance to pay for time off due to SUD due to providing incomplete info.</i></p> <p><i>When clients have a company contract rehab to prove they had treatment if no release this stops clients from receiving their drivers license, proof of treatment for their jobs etc in timely manner.</i></p>
They make it difficult to	6		<p><i>...it is nearly impossible to perform targeted quality assurance of programs initiated in the healthcare setting on outcomes as we are</i></p>

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evaluate programs and improve services			<i>unable to gather patient specific follow up information without overcoming multiple hurdles. The removal of particularly and unusually stringent PA confidentiality restrictions and transition to federally directed confidentiality standards would not remove patient confidentiality protections. Patient's healthcare information would remain protected, confidential, and inaccessible by outside agencies outside of specified scenarios.</i>
They perpetuate stigma by setting SUD apart from other health conditions	12	<ul style="list-style-type: none"> <li>• Creates chilling effect; fear of regulations prevents expansion of SUD care</li> <li>• Fosters shame</li> <li>• Holds the field back from progress</li> <li>• Limits overdose prevention</li> <li>• Not feasible, inefficient</li> <li>• Treat SUD like medical condition</li> <li>• Why are SUD confidentiality requirements more restrictive than mental health's?</li> </ul>	<p><i>They promulgate the perception that people should be ashamed of themselves and their illness.</i></p> <p><i>On the one hand, there is the mantra to "reduce stigma", yet the regs promote "hiding in the closet". You can't have it both ways. Either treat SUD with the same openness as other MH and Medical disorders, or stay hidden in the closet. Pick one.</i></p> <p><i>While I see the value in having limits to information and understand that the reality is SUDs are still stigmatized in our culture, I do believe that by silo-ing care perpetuates the stigma. It also does not allow for a person to have integrated care when parts of their health history may be hidden from their doctor(s). Many health care professionals, however will need significant training in working with people who have an SUD so they are treating people with dignity and respect.</i></p>
<b>18.2% cited challenges but also indicated benefits or room to improve OR response was unclear (n=55)</b>			
Challenging to interpret the current requirements	7	<ul style="list-style-type: none"> <li>• Confusion around parameters of disclosure (who can receive what info, under what circumstances)</li> <li>• Need more or better resources to train/educate stakeholders about confidentiality/requirements</li> <li>• Need regulatory language to be clearer, simplified</li> <li>• Particular concerns about recovery houses</li> <li>• Protects providers from litigation</li> </ul>	<p><i>My main issue is I believe we need more plain language documents explaining the laws and codes. I don't want to see LESS confidentiality for persons with SUD, but I'd like to see the governing documents more streamlined and less complicated.</i></p> <p><i>I have seen some gray area with regards to Recovery Houses.</i></p> <p><i>Providers/Clinician appear to be somewhat unsure of what information they can and can't provide. I notice many providers feel they can't provider other clinicians/providers information with consent due to not understanding or uncertainty regarding the regulations.</i></p>

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<p>Knowledge/understanding of the SUD confidentiality requirements is the challenge, not the requirements themselves</p>	<p>12</p>	<ul style="list-style-type: none"> <li>• Cited challenges have to do with challenges of compliance, not challenge to clients</li> <li>• Need more/better training on regulations</li> </ul>	<p><i>I do not think it is the laws that is the issue. I believe it is the misunderstanding of the complexities of an SUD as well as a lack of knowledge with the recovery process.</i></p> <p><i>The only challenges is the lack of understanding. If you are very knowledgeable of the confidentiality laws and the person on the other end is not, it can look as if you're attempting to withhold information when you're actually protecting the client to avoid stigma.</i></p> <p><i>Need far more training to understand the rules.</i></p> <p><i>Outside agencies are not educated and do not see the importance of having regulations so clients are not fearful of seeking treatment.</i></p>
<p>Compliance with/acceptance of the requirements is the challenge, not the requirements themselves</p>	<p>13</p>	<ul style="list-style-type: none"> <li>• Challenge is for entities trying to obtain data, not orgs trying to comply with requirements</li> <li>• Client protection should not be sacrificed for convenience</li> <li>• Entities that are "blocked" from data by regs persist, sometimes aggressively</li> <li>• Mistrust of specific entities: criminal justice</li> <li>• Pressure from entities trying to obtain info leads to confidentiality breaches</li> <li>• Protect client from harm: legal repercussions</li> <li>• Specific issues in rural areas (familiarity with people)</li> <li>• SUD confidentiality requirements in PA stricter than in other health areas like mental health</li> <li>• There are ways to get data while still complying with requirements</li> </ul>	<p><i>The problem with the confidentiality regulations is that many people from courts and insurance companies are not educated about them... If these regulations are impeding- I would strongly suggest it is because people are not upholding them. Effective treatment exists when trust is built. There is still too much stigma to reduce the requirements</i></p> <p><i>Many of these entities are thinking of their own wants and are forgetting or disregarding the needs and safety of the patients. Please understand that while people are living through their addictions, they often engage in activities that run afoul of the law. We are about making a social contract with these individuals. That social contract states that if a person comes off the street and into treatment, we will not use any of the information obtained through the treatment process to take any criminal, administrative or civil actions against those individuals.</i></p>
<p>Miscellaneous Response</p>	<p>10</p>	<ul style="list-style-type: none"> <li>• Burdens the client</li> <li>• Consent process</li> <li>• Need more flexibility now because of COVID</li> </ul>	<p><i>With the current pandemic and telemedicine acceptance, getting releases from clients has created a barrier to holistic care.</i></p> <p><i>In some ways this allows addictive behaviors to continue as you are not allowed to discuss why the patient was discharged from your services or concerns that you had about them prior to them changing providers. Unfortunately, i'm not sure there will be a one size fits all confidentiality for SUD due to the complexity of the population....</i></p>

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Unclear Response / Incomplete	13		
<b>6% did not cite a challenge and/or expressed support for current requirements (n=18)</b>			
No challenges with current requirements	5		<p><i>Really no impact here. A client is always free to obtain the information and do whatever they wish with it.</i></p> <p><i>PA's confidentiality requirements are not the primary reason why SUD tx is ineffective.</i></p>
No cited challenge, expressed support or a need for requirements	8	<ul style="list-style-type: none"> <li>• Help providers protect/help the client</li> <li>• Problem is drug criminalization policies, not confidentiality requirements</li> <li>• Protect client from harm: bad actors</li> <li>• Protect the client from criminal prosecution or criminal justice entities</li> </ul>	<p><i>Because of the stigma surrounding substance use disorders, strict confidentiality regulations are required.</i></p> <p><i>Yes, people who want to get the data to sell it, or deny care. Changes in the requirements make it harder to trust and engage in treatment.</i></p> <p><i>Once someone finds out you are on Methadone or Suboxone patient get treated like they are underclass</i></p>
Benefits outweigh challenges	5	<ul style="list-style-type: none"> <li>• Offers protection to clients and providers</li> </ul>	<p><i>I don't believe it's the responsibility of the confidentiality regulations to prevent negative consequences for the client... The confidentiality regulations are to support the client and the clinicians who serve them in providing only the information necessary to those entities who can use that information control or influence the outcomes for the individual (i.e. insurance companies, courts/probation/parole, CYS, DRS).</i></p> <p><i>There may be challenges for providers, but the clients lives are at stake. It is worth the challenges.</i></p> <p><i>Sharing of information with other professionals in a healthcare setting does not always serve the needs of the patient.</i></p>