

# **S U M M A R Y   R E P O R T**

Stakeholder Assessment of Pennsylvania's  
Substance Use Disorder Confidentiality Policies



## REPORT AUTHOR

Alex Shirreffs, MPH  
Seconded to DDAP via Vital Strategies  
c-ashirref@pa.gov  
717-736-7486

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Cartwright-Smith, Gray, & Thorpe, *Pennsylvania Law & Policy Governing the Confidentiality of Substance Use Treatment Information: Challenges & Opportunities* (2019)  
[http://www.healthinfolaw.org/PA\\_substance\\_use\\_information\\_confidentiality](http://www.healthinfolaw.org/PA_substance_use_information_confidentiality)

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## DEFINITION OF TERMS

<b>Clients</b>	People engaging with SUD treatment and/or support services are referred to as clients.
<b>Health Hub Agencies</b>	Five Pennsylvania agencies make up the Health Hub, including the Department of Aging, Department of Drug and Alcohol Programs, Department of Health, Department of Human Services, and Pennsylvania Insurance Department.
<b>Part 2</b>	Under the Code of Federal Regulations (CFR), 42 CFR Part 2 outlines federal regulations overseeing the Confidentiality of Substance Use Disorder Patient Records. Part 2 applies to any individual or entity that is federally assisted and holds itself out as providing, and provides, alcohol or drug abuse diagnosis, treatment, or referral for treatment (42 CFR § 2.11 - 2.12).
<b>Participants</b>	People who participated in the survey or interviews and provided insight to this report.
<b>People living with SUD</b>	This includes people at all stages of the SUD spectrum, from people who are currently in active addiction to those in treatment for or in recovery from SUD.
<b>SUD confidentiality policies</b>	<p>For brevity, “policies” is not used as a legal term in this report but as a shorthand to discuss Pennsylvania’s main statutes and regulations pertaining to the confidentiality of a person’s SUD records:</p> <ul style="list-style-type: none"> <li>• The Pennsylvania Drug and Alcohol Abuse and Control Act, also known as Act 1972-63 (See 71 P.S. § 1690.108)</li> <li>• 4 Pa. Code § 255.5; compliance with Section 255.5 is written into the regulations of mental health and psychiatric treatment providers (See e.g., 55 Pa. Code § 5100.37)</li> <li>• 28 Pa Code § 709.28</li> </ul> <p>While the assessment and report describe these as a collective, there are legal differences:</p> <ul style="list-style-type: none"> <li>• 71 P.S. § 1690.108 is a statute. <ul style="list-style-type: none"> <li>○ Statutes are laws passed by the legislature.</li> </ul> </li> <li>• 4 Pa. Code § 255.5 and 28 Pa Code § 709.28 are regulations. <ul style="list-style-type: none"> <li>○ Regulations are agency rules promulgated through the regulatory review process that must be within their statutory authorities but have the force and effect of law.</li> </ul> </li> </ul> <p>No commonwealth agency can unilaterally change statute or regulation.</p>

## **ACRONYMS**

CDC	Centers for Disease Control and Prevention
CFR	Code of Federal Regulations
DDAP	Pennsylvania Department of Drug and Alcohol Programs
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
HPA	Human Protection Administrator
IRB	Institutional Review Board
MCO	Managed Care Organization
OFR	Overdose Fatality Review
SUD	Substance Use Disorder

# Executive Summary

In 2020, the Pennsylvania Department of Drug and Alcohol Programs (DDAP) invited stakeholders to provide feedback on Pennsylvania’s substance use disorder (SUD) confidentiality policies – a set of statutes and regulations that control the management of SUD records in the Commonwealth.

- [The Pennsylvania Drug and Alcohol Abuse and Control Act](#), also known as Act 1972-63, is a statute that applies to records of SUD history, including diagnosis and/or treatment, prepared or obtained by any SUD or medical provider. See [71 P.S. § 1690.108](#).
- [4 Pa. Code § 255.5](#) is a DDAP regulation that limits the information and recipients of disclosure of client information by SUD projects and coordinating bodies. Compliance with Section 255.5 is written into the regulations of mental health and psychiatric treatment providers. See, e.g., [55 Pa. Code § 5100.37](#).
- [28 Pa Code § 709.28](#) is a regulation that applies confidentiality standards to treatment activities licensed by DDAP.

Over 1,200 stakeholders shared feedback through an online survey. Interviews with seventy individuals added additional context to survey insight. Participants of both represent diverse experiences including people living with SUD, people within the drug and alcohol community and from other sectors that engage with people living with SUD including physical and behavioral health care providers, criminal justice entities, and payors. This report describes:

- Why a majority of stakeholders support changes to Pennsylvania’s policies.
- How stakeholders want to see Pennsylvania’s policies change.
- Opportunities and apprehensions to consider when updating Pennsylvania’s policies.

A majority of people across stakeholder types want Pennsylvania’s SUD confidentiality policies updated.

The recommendations outlined in this report ask stakeholders to consider a shift in Pennsylvania’s approach to confidentiality of SUD records. The Commonwealth’s current policies, developed in the 1970s when the SUD and health care landscapes looked quite different, approach protection of records by limiting access to information, sometimes even in cases when a client consents to it being shared.

This report uses feedback from stakeholders, who describe evolving SUD and health care systems, to propose updates to confidentiality that would allow clients to more freely determine which entities may have access to their records. For this shift to happen, people living with SUD must trust that they will not be pressured into consenting to a release of records, that all systems with access to their records will have safeguards in place to protect their personal data, and that they will not be stigmatized because of their SUD history.

The recommended changes to SUD confidentiality in Pennsylvania reflect stakeholder views that data can be shared better between different providers caring for a client and still be protected. There may also be another benefit: access to SUD records may help protect people living with SUD from future overdoses and other poor health outcomes. These recommendations offer a new model of SUD confidentiality in Pennsylvania that allows for the expansion of person-centered care in a landscape of services for people living with SUD that is increasingly more integrated and collaborative. In the context of this report, changes to Pennsylvania's policies would still require clients' consent to share their record (aside from exceptions outlined in 42 CFR Part 2).

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## Key Findings

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### **Attitudes towards Pennsylvania's current SUD confidentiality policies.**

Pennsylvania is one of three states that has SUD confidentiality policies that go above and beyond federal SUD confidentiality regulations contained in 42 CFR Part 2. While most stakeholders agree that protecting a person's privacy is important, only a minority of stakeholders believe Pennsylvania's policies should remain in their current form.

### **Strengths of current policies:**

- 60.7% of survey participants agree that the current policies help people feel comfortable seeking SUD treatment because their privacy will be protected.
- Ensuring clients feel protected and that their SUD record will remain confidential helps build trust between people living with SUD and their treatment and care providers.
- There is a perception that the current policies protect people living with SUD from stigma and discrimination and prevent a person's SUD history from being used against them.

### **Challenges of current policies:**

- 79.5% of survey participants agree that current policies lead to exclusion of SUD from client records, resulting in an incomplete client history for a person's other care providers.
- 67.4% of survey participants agreed the current policies are too restrictive about which entities can receive data, even when individuals give consent for their record to be released.
- Stakeholders described how the policies pose barriers to care coordination, service integration, and program evaluation.
- 55.1% of survey participants believe that the current policies perpetuate stigma; they described how separating SUD from other health information contradicts messaging that SUD is a chronic illness that should be treated like other health issues.

**Attitudes towards changing Pennsylvania's policies.** This report finds that there is strong support for updating Pennsylvania's SUD confidentiality policies across stakeholder

groups, but stakeholders want to be confident that changes will do more good for people living with SUD than harm.

#### **Benefits of change:**

- Most survey participants feel that federal privacy protections are sufficient - 63.9% agree Pennsylvania does not need SUD confidentiality policies that are more restrictive than federal regulations.
- Proponents of change believe it will make it easier for providers to support clients by improving care coordination, integrated SUD services, and communication between a client's providers.
- Clearer policies will improve consistency and compliance with confidentiality requirements.

#### **Concerns about change:**

- There is more uncertainty about changing Pennsylvania's policies than there is opposition to change; stakeholders are open to change but want assurance that changes will help, more than harm, people living with SUD.
- Changing Pennsylvania's confidentiality policies could result in a perception that privacy has weakened; some stakeholders are concerned this could prevent people living with SUD from seeking care.
- While people receiving SUD treatment will still need to give consent for their record to be shared, there is concern changes could make clients more vulnerable to data misuse or discrimination.

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## Survey Recommendations

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The vast majority of stakeholders surveyed - 80.9% - believe Pennsylvania's SUD confidentiality policies can be improved. Across different questions, only a minority of stakeholders prefer to keep the current policies in place. More stakeholders have uncertainty about change than oppose change; they want assurance that any changes to Pennsylvania's policies benefit people living with SUD more than they may cause unintended harm.

These recommendations, developed from stakeholder feedback, pose an opportunity to modernize Pennsylvania's approach to SUD confidentiality in a way that both protects and empowers people living with SUD. The goal of these proposed changes is to update Pennsylvania's SUD confidentiality policies to meet the needs of an evolving SUD service landscape that is becoming increasingly integrated with physical and behavioral health and other social services. Recommendations include examples of strategies from other states that Pennsylvania can adapt to meet the needs of our unique systems and stakeholders.

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### **Survey Recommendation 1: Modernize Pennsylvania's SUD confidentiality policies.**

*Align Pennsylvania's SUD confidentiality requirements with federal privacy protections.*

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Most survey participants - 63.9% - do not think Pennsylvania needs SUD confidentiality policies that go above and beyond federal SUD confidentiality regulations. There is support for amending Pennsylvania's statutes and regulations to better reflect Pennsylvania's current spectrum of SUD services and provide more flexibility for these services to be coordinated among different providers. Through legislation, challenges to both 71 P.S. 1690.108 (statute) and 4 Pa. Code § 255.5 (regulation), along with related provisions of statute and regulation, could be addressed at once through alignment with the federal framework established by the Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2.

When asked to select specific aspects of the current SUD confidentiality policies that are challenging for stakeholders, over half of survey participants identify these limitations of the various policies:

- Exclusion of SUD from client records gives providers an incomplete client history.
- Too restrictive about which entities can receive data, even with client consent.
- Difficult to integrate SUD services in health care settings.

- Difficult to evaluate programs and improve services.

Because these challenges are linked to language in both statute and regulation, using legislative action to make revisions would allow for several areas of conflict to be addressed at one time. This would also align Pennsylvania with the 47 other states in the nation that have SUD disclosure requirements that are controlled by Part 2 and would make it easier for Pennsylvania to adapt when federal regulations are adjusted to account for changes in the SUD field in the future. Stakeholders hope for these improvements to SUD confidentiality in Pennsylvania, which could be achieved if state policies are revised to align with federal regulatory language:

- Strengthen client control over records by allowing them to determine for themselves how much information can be shared with any entity.
- Update to reflect changes in the field including integration of services and health information technology.
- Make policies clearer and more well-defined.
- Improve communication and collaboration between entities serving people living with SUD.

Stakeholders believe updating Pennsylvania's policies will enhance care for people living with SUD by improving integration and care coordination between SUD providers and other health and social service entities (including behavioral and physical health services). Failure to modernize our policies will perpetuate confusion because providers will have to navigate two different sets of confidentiality requirements – state policies that uphold a siloed model of SUD care, and federal policies that account for innovations in the SUD and healthcare fields.

### **Examples from other jurisdictions:**

This map includes links to SUD confidentiality statutes and regulations from other states:

- *Disclosure of Substance Use Records with Patient Consent: 50 State Comparison*
  - <http://www.healthinfolaw.org/comparative-analysis/disclosure-substance-use-records-patient-consent-50-state-comparison-0>

## **Survey Recommendation 2: Protect and empower people living with SUD.**

*Develop resources on client privacy rights.*

*Establish a clearer pathway for clients to report grievances if they think their data has been misused or if they feel their SUD status has resulted in discrimination.*

Over half (53.8%) of surveyed stakeholders agree that even the current policies do not fully protect clients from negative consequences. But stakeholders who are uncertain about changing Pennsylvania's SUD confidentiality policies want assurance that updating these policies will not harm privacy so much that it discourages clients from entering treatment or lead to an increase in harm from improper use of data. To be clear, any changes to Pennsylvania's policies will not remove the need for a client consent to share their record, per federal regulations.

Changes to Pennsylvania's SUD confidentiality policies should be accompanied by measures to ensure that all individuals who enter SUD treatment in Pennsylvania are informed about their rights over their own records and know what measures they can take if they think their data has been misused or if they think they have been treated unfairly because of their history of SUD. DDAP could develop clear materials on confidentiality and privacy to share with providers for distribution to clients and make these available through its website.

Some stakeholders note that because substance use is so stigmatized, people living with SUD may not feel empowered to report situations when they have experienced harm or discrimination. DDAP could enhance client support by exploring other states' measures such as regulations to establish a client bill of rights, clarifying the process for managing client grievances, or assigning an ombudsman or advocate to help clients navigate the reporting process. A benefit of improving the reporting and mediation process for confidentiality is that it could expand to improve the management of complaints and grievances in the SUD treatment system more broadly.

### **Examples from other jurisdictions:**

Neighboring states clearly outline client rights and describe the process for reporting complaints. In some cases, there is a designated state official who specializes in managing grievances:

- New York State Office of Addiction Services and Supports: Rights and Protections While in Treatment
  - <https://oasas.ny.gov/system/files/documents/2020/01/patient-rights-and-responsibilities-brochure.pdf>
- Ohio Department of Mental Health and Addiction Services: Rights and Advocacy Resources
  - <https://mha.ohio.gov/Families-Children-and-Adults/Get-Help/Client-Rights>
- New Jersey Department of Mental Health and Addiction Services: Ombudsman
  - <https://www.state.nj.us/humanservices/dmhas/home/Ombudsman%20flyer%20October%202019.pdf>

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### **Survey Recommendation 3: Train and inform SUD stakeholders.**

*Publish and disseminate guidance materials to summarize changes to SUD policies.*

*Update DDAP's confidentiality training to reflect policy changes and offer a skills-based component to help providers effectively counsel clients on consent.*

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Many stakeholders describe Pennsylvania's current SUD confidentiality policies as confusing, particularly the interplay between various state regulations and statutes as well as the interplay of state and federal policies. Over half of surveyed stakeholders support revisions that make confidentiality requirements clearer and more well-defined (58.5%) and support guidance materials to clarify confidentiality requirements (57.2%). Aligning Pennsylvania's policies with federal confidentiality regulations would simplify the set of confidentiality policies providers must comply with.

But some stakeholders raised a concern that changing Pennsylvania's longstanding policies would be an adjustment for providers and emphasized that the SUD field must be supported in navigating these changes with training and education. This is especially important because a concern some stakeholder expressed about changing Pennsylvania's policies is that clients might not enter treatment if the state-specific policies change. It is essential that providers understand what protections will remain and how they can adapt their messaging to clients when describing privacy rights to ensure clients know their records will still be protected.

Updates on changes to SUD confidentiality policies should be shared through a variety of formats. DDAP can release a guidance document as soon as any changes are finalized but should also offer presentations to stakeholder groups to explain changes and identify whether

additional tools are needed to help clarify changes for stakeholders. This is also an opportunity to promote resources for people living with SUD that are developed per Recommendation 2.

Since the current SUD confidentiality training already focuses heavily on educating stakeholders about federal Part 2 regulations DDAP could continue to use its existing Drug and Alcohol Confidentiality curriculum. Revisions to address stakeholder concerns could include adding information about HIPAA protections since this federal privacy rule protects a person's health information across systems of care and adding information about how confidentiality protections are enforced. To address provider uncertainty advising clients on confidentiality, DDAP could revise its Practical Applications of Confidentiality training to include scenarios that help providers practice messaging and counseling skills so they can help clients make informed decisions about consenting to release of information including harms and benefits.

## PROJECT BACKGROUND

In 2020, DDAP conducted an assessment to understand stakeholder attitudes on Pennsylvania’s SUD confidentiality policies. Its purpose was to determine if and how policies can be improved to promote the health and wellbeing of people living with SUD. DDAP developed this assessment with two guiding questions:

- Do current SUD confidentiality policies – and/or the perceptions of these policies – affect access to care for people who are enrolled in or in need of SUD services in Pennsylvania?
- How can Pennsylvania address challenges and concerns with SUD confidentiality policies in a way that maximizes benefits to people in need of SUD services and minimizes harm while protecting client data?

This report summarizes the assessment results. Its goal is to inform leadership on how the commonwealth’s unique SUD confidentiality policies affect access to and delivery of SUD services and supports. Feedback from the field informs recommendations that Pennsylvania leaders can consider to improve care and support for people living with SUD.

**Public-Private Partnership to Reduce Overdose Fatalities in Pennsylvania.** The Wolf Administration has made addressing drug overdoses a top priority. In 2018, Bloomberg Philanthropies committed resources to support this effort through investments in policy reform, innovative programs, and community mobilization. Vital Strategies, Bloomberg’s technical assistance and implementation provider, is working in coordination with the Wolf Administration to implement projects tailored to the specific needs of Pennsylvania.

### How this report uses the term “SUD confidentiality policies”

The term “SUD confidentiality policies” covers the three main Pennsylvania statutes and regulations that control the confidentiality of a person’s SUD records.

- [The Pennsylvania Drug and Alcohol Abuse and Control Act](#), also known as Act 1972-63, is a statute that applies to records of SUD history, including diagnosis and/or treatment, prepared or obtained by any SUD or medical provider. See [71 P.S. § 1690.108](#).
- [4 Pa. Code § 255.5](#) is a DDAP regulation that limits the information and recipients of disclosure of client information by SUD projects and coordinating bodies. Compliance with Section 255.5 is written into the regulations of mental health and psychiatric treatment providers. See, e.g., [55 Pa. Code § 5100.37](#).
- [28 Pa Code § 709.28](#) is a regulation that applies confidentiality standards to treatment activities licensed by DDAP.

This report provides a table comparing Pennsylvania’s policies with federal regulations in **Appendix A**.

#### ***For additional background on these policies:***

In 2019, George Washington University’s Health Information and the Law Project issued a report summarizing the commonwealth’s confidentiality landscape as well as resulting gaps and possible options for addressing challenges.

- *Pennsylvania Law & Policy Governing the Confidentiality of Substance Use Treatment Information: Challenges & Opportunities:*  
[http://www.healthinfolaw.org/PA\\_substance\\_use\\_information\\_confidentiality](http://www.healthinfolaw.org/PA_substance_use_information_confidentiality)

DDAP identified SUD confidentiality as a policy issue that could benefit from this evaluation. Vital Strategies provided the department a seconded staff (the Project Manager) to 1) conduct a stakeholder assessment to examine how the commonwealth's policies have hindered and/or facilitated access to substance use services and 2) use this feedback to offer recommendations to improve these policies.

## Do SUD Confidentiality Policies Help or Hinder Pennsylvania's Response to its Addiction and Overdose Crisis?

In the last five years (2015-2019), overdoses took the lives of over 21,907 Pennsylvanians – about 12 people each day.<sup>i</sup> The US Centers for Disease Control and Prevention (CDC) estimates that over 300,000 Pennsylvania residents are living with SUD (not including alcohol).<sup>ii</sup> Our commonwealth has one of the highest overdose death rates in the nation (35.6 per 100,000).<sup>iii</sup> Aside from the human costs of this crisis, there is also an economic cost. One report found that in 2016 the opioid crisis cost Pennsylvania over \$53 billion in fatalities, health care spending, addiction treatment, criminal justice, and lost productivity.<sup>iv</sup> The increase in synthetic opioids such as fentanyl, changing drug use trends, and the COVID-19 pandemic have accelerated overdose deaths nationwide. At the end of 2020, CDC warned states to expect increases in drug overdose deaths.<sup>v</sup>

DDAP decided that the scope of Pennsylvania's overdose and addiction crisis warrants an assessment of state-specific SUD confidentiality policies. In reviewing stakeholder feedback to develop recommendations for action, the stakes of change were not taken lightly. Whether for or against change, stakeholders understand that the lives of people who use drugs and people living with SUD are at stake, as reflected in these survey responses.

- **In support of current policies:** *“One of the only reasons people are willing to reach out for assistance is due to the confidentiality protections currently in place. Changing them will cost us lives.”*
- **In support of updating policies:** *“I believe that privacy is so strictly protected that lives are lost for the sake of confidentiality...”; “The benefits greatly outweigh the risks - this will help save lives.”*

There are a growing number of evidence-based strategies and tools to prevent overdoses and support people living with SUD. Is Pennsylvania able to maximize the tools at its disposal to mitigate the effects of this statewide public health crisis? Every overdose is an opportunity for key decision makers to assess whether Pennsylvania's policies, including SUD confidentiality policies, help or hinder efforts to save lives.

## History of SUD Confidentiality in Pennsylvania

**Origins of Pennsylvania's Policies.** Nearly fifty years ago, Pennsylvania took steps to protect the privacy of people seeking SUD treatment because 1) federal policies protecting health information that we have today did not exist and 2) advocates recognized that stigma contributed to a fear of disclosure that could prevent people in need of SUD treatment from entering or staying in care. Between 1972 and 1985, Pennsylvania enacted its own SUD confidentiality policies. Stakeholders credit them for ensuring confidentiality is valued as critical in building a foundation of trust between treatment providers and people in the vulnerable position of seeking help.

**Evolution of Federal Privacy Policies.** SUD information in a person's health records is primarily regulated at the federal level by:

- [42 CFR Part 2](#) (established in 1975), which governs the confidentiality of SUD client records obtained by federally assisted programs, and

- [Health Insurance Portability and Accountability Act \(HIPAA\)](#) (established in 1996), which protects individuals' information held by Covered Entities (including healthcare providers, health plans, and healthcare clearinghouses) and their business associates.

Over the years, the federal government revised its privacy policies to address changes in the field including electronic data security, expansion of health information exchanges, health systems integration, proliferation of team-based models of care, and individuals' rights to access their own records.<sup>vi,vii</sup> Changes in how society views SUD also contributes to evolving policies.

**Evolution of Attitudes Towards SUD.** The 1970s, when Pennsylvania's SUD confidentiality policies were first enacted, saw the launch of the War on Drugs. This national policy strategy intensified societal stigma; it framed addiction as a moral failure, historically directed more funding towards supply reduction (such as law enforcement and criminal justice efforts) than demand reduction (including treatment and prevention), and drove inequitable enforcement of penalties for drug use.<sup>viii, ix</sup> Like other stigmatized conditions, such as mental health diagnoses or HIV, the SUD treatment system grew in a silo out of necessity; mainstream health, medical and social service systems either lacked capacity or refused to provide care for people living with SUD.

In recent years, a national explosion in overdose deaths and the opioid crisis have shifted society's view of addiction. A landmark 2016 Surgeon General report summarized the shift to framing SUD as a public health issue:

*For far too long, too many in our country have viewed addiction as a moral failing. This unfortunate stigma has created an added burden of shame that has made people with substance use disorders less likely to come forward and seek help. It has also made it more challenging to marshal the necessary investments in prevention and treatment. We must help everyone see that addiction is not a character flaw – it is a chronic illness that we must approach with the same skill and compassion with which we approach heart disease, diabetes, and cancer.<sup>x</sup>*

Challenges remain for people living with SUD including stigma, the criminalization of substance use, parity for SUD and behavioral health treatment, access to non-judgmental health care, and racial and ethnic disparities in access to treatment. A growing understanding of these challenges have led more systems – health care, mental health, criminal justice systems and others - to recognize their role in supporting people living with SUD to mitigate the devastating impacts of this illness on our communities.

**Is it Time for Pennsylvania's Policies to Evolve?** Pennsylvania's SUD confidentiality policies are an outlier: we are one of only three states (including Oklahoma and Kansas) that goes above and beyond Part 2. In every other state, SUD confidentiality policies align with Part 2.<sup>xi</sup>

In 2008, the Pennsylvania Department of Health proposed changes to 4 Pa. Code § 255.5 that would move it into closer alignment with federal regulations.<sup>1</sup> Proponents of change believed updating it would improve care for people living with SUD.<sup>xii</sup> Opponents feared that changing Pennsylvania's regulations would weaken privacy and deter people from treatment. The proposed changes did not move forward but the question of whether Pennsylvania's policies help or hinder access to SUD services has persisted over the years.

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<sup>1</sup> The Pennsylvania Department of Health housed the Bureau of Drug and Alcohol Programs until 2012, when DDAP was established through Act 50 of 2010.

Since 2008, over 30,000 Pennsylvanians have died of a drug overdose.<sup>xiii</sup> It is still critical to protect the privacy and confidentiality of people living with SUD. But, given the scale of Pennsylvania's overdose crisis, it is also important to increase entry points to SUD services and steer more people living with SUD towards treatment and support. This assessment revisits questions that have lingered since 2008. Are Pennsylvania's SUD confidentiality policies an impediment to the expansion of services for people living with SUD? Do they inhibit the coordination of care for people living with SUD? To develop recommendations, stakeholders were also asked to share insight into how they would like to see Pennsylvania's policies improve.

## METHODS

### Scope of Work

The Project Manager developed stakeholder assessment instruments to help DDAP and its partners better understand beliefs, practices and barriers related to Pennsylvania's SUD confidentiality policies. Assessment activities included an online survey and stakeholder interviews. They identified how Pennsylvania's policies impact the delivery of services to people living with SUD and informed the recommendations provided at the beginning of the report.

### Survey Instrument

The primary data collection method for the stakeholder assessment was an online survey. The goals of the survey were to identify 1) stakeholder positions and experiences related to Pennsylvania's current SUD confidentiality policies and 2) strategies to address challenges and concerns with Pennsylvania's current policies. The final survey instrument (provided in Appendix B) consisted of 19 fixed-choice and free-text questions divided into four sections:

- **Consent to participate.** A detailed consent statement provided information about the purpose of the survey and described how the Project Manager would store and use the data. After reviewing this statement, participants could consent to proceed or close the survey.
- **Participant background.** Six questions collected information about participants' background.
- **Attitudes towards Pennsylvania's current SUD confidentiality policies.** Seven questions asked participants to share their experience with and attitudes towards Pennsylvania's current policies.
- **Attitudes towards revising Pennsylvania's SUD confidentiality policies.** Five questions asked participants to share attitudes and insight on possible revisions to the current policies.

### Participant Protections

The survey was anonymous, and participation was voluntary. The Project Manager designed survey questions that minimized the collection of identifying information. Before its launch, DDAP and Vital Strategies staff piloted, reviewed, and approved the survey instrument.

The Project Manager, the only person with access to the raw data files, took several steps to ensure protection of participant data. She completed a Human Subjects Research training and submitted a protocol for review by Vital Strategies' Human Protection Administrator (HPA). The HPA determined that data collection and storage protocol were secure and that the informed consent process was appropriate. A full Institutional Review Board (IRB) review was not necessary since 1) a government body administered assessment activities for the exclusive purpose of improving quality of care and 2) stakeholder feedback will not be used to develop or contribute to generalizable knowledge.<sup>2</sup>

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<sup>2</sup> If an activity involving human subjects were determined to be research, an Institutional Review Board would review the study protocol to ensure that it complies with applicable regulations, meets accepted ethical standards, follows institutional policies, and protects research participants.

## Survey Distribution

The Project Manager used electronic distribution to maximize the reach of the survey. SurveyMonkey, an online survey software platform, hosted the survey. It stayed open from 13 May 2020 through 31 August 2020. Anyone could complete the survey. Participants were recruited using a convenience sampling approach. All communications about the survey encouraged participants to share the survey link within their networks. While the complete breadth of the survey's reach is unknown, survey distribution included the following actions:

- DDAP sent the survey link to its listserv, which reaches approximately 1,300 people.
- DDAP posted a project page to its website, which included a survey link and background information on the stakeholder assessment.<sup>xiv</sup>
- At least 15 agencies, trade organizations, and governmental partners informed the Project Manager that they distributed the survey link to their networks.
- Policy and Intergovernmental Affairs staff in other Health Hub agencies distributed to appropriate stakeholder groups in their networks.
- The Project Manager met with stakeholder groups to provide a project overview and encourage participation in the survey.

## Interviews

While this report primarily summarizes survey results, it also includes a few interview anecdotes. The Project Manager supplemented survey feedback by conducting interviews with 70 people representing approximately 30 different entities between March and September 2020.<sup>3</sup> These semi-structured interviews helped the Project Manager explore themes emerging from the survey in more detail and hear more about stakeholders' experiences with Pennsylvania's SUD confidentiality policies in their life and work.

The Project Manager recruited interview participants by inviting stakeholders who could represent a diversity of opinions. A snowball sampling approach was used, starting with recommendations for participants from DDAP staff. The Project Manager also asked for additional suggestions from each interview participant. Survey outreach included the Project Manager's contact information so stakeholders could also reach out to coordinate an interview if they wanted to share insight.

The Project Manager conducted interviews virtually due to COVID-19 safety measures. As part of the consent agreement, the Project Manager developed a security protocol to ensure the protection of interview subjects' confidentiality. Interview participants consented to participate before the interview started.

## Data Analysis

The Project Manager uploaded survey results from SurveyMonkey into IBM SPSS Statistics software and conducted simple descriptive analyses by tabulating frequencies and calculating crosstabs. Because the purpose of the assessment is not for research, the results analysis is descriptive and did not use inferential statistical methods to analyze results. While the interview results were not analyzed quantitatively, the report cites a few interview anecdotes to provide real-world context to findings from the survey themes.

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<sup>3</sup> The number of entities is approximate because some people represented more than one entity or represented different divisions within a larger entity.

## Limitations

While an online survey was a cost-effective and timely method for survey distribution, it meant relying on a convenience sample of respondents. The limitations of using a convenience sample were twofold. It prevents the ability to calculate a survey response rate since the number of stakeholders who received a link to the survey is unknown. It also subjected the survey to selection bias. DDAP distributed the survey to a diverse set of stakeholders, but it is possible that entities or individuals with interest in the subject did not receive the link or may not have been able to complete the survey online. While a PDF version of the survey was not posted online, the Project Manager shared it with interested stakeholders by request.

The Project Manager tried to address the challenge of reach by working with colleagues to identify leaders in the field to help distribute the survey and recruit participants and by encouraging survey and interview participants to share the survey link or put other individuals in touch with the Project Manager to schedule an interview.

That said, it is possible that the complexity of the subject resulted in a selection bias in that at least a basic understanding of Pennsylvania's SUD policies would have been helpful to provide an informed response to the survey and interview questions. People with less awareness of the nuances of these policies might have found it challenging to ascribe benefits or challenges to a specific statute or regulation or to compare Pennsylvania policies to federal policies. Given that most survey participants addressed the need to clarify and/or simplify Pennsylvania's policies, Recommendation 1 attempts to address this limitation by making Pennsylvania's policies clearer through alignment with federal regulations.

This report is also limited in how much it could address the complexity of the subject of confidentiality, both in the data collection as well as in summarizing the findings. This report describes attitudes towards a specific group of Pennsylvania policies regulating the confidentiality of SUD records. A challenge of these policies is that, while DDAP is responsible for regulating them, they affect other intersecting fields including physical health, behavioral health, child welfare, criminal justice, payors and insurers, public health surveillance, and other social services. While these entities participated in surveys and interviews, this report could not provide detailed context for all the ways in which the interplay of each different statute or regulation uniquely affects these different stakeholder groups.

## **SUMMARY OF FINDINGS**

The final survey data set consists of **1,267** valid survey participants. This data set includes both complete and partial survey responses. While 1,614 participants consented to proceed with the survey, these findings remove incomplete responses from the data set if participants did not reply to any questions at all (n=174) or if they skipped all questions asking for input on the SUD confidentiality requirements (n=173).

The survey asked participants to draw on their personal and/or professional experience with SUD to provide insight into Pennsylvania's current SUD policies and possible revisions to Pennsylvania's policies. This summary of findings is organized by sections of the survey:

### **Participant background:**

- Experience with SUD.
- Experience with confidentiality.

### **Attitudes towards Pennsylvania's current SUD confidentiality policies:**

- Benefits associated with the current policies.
- Challenges associated with the current policies.
- Does Pennsylvania need SUD confidentiality policies that go above and beyond the federal regulations?

### **Attitudes towards revising Pennsylvania's SUD confidentiality policies:**

- How can Pennsylvania's SUD Confidentiality Policies be improved?
- How could aligning Pennsylvania's policies with federal regulations improve care for people living with SUD?
- How could aligning Pennsylvania's policies with federal regulations challenge care for people living with SUD?

## Section Snapshot

### Participant Background

- Results represent a diversity of stakeholder experiences, including people within the drug and alcohol community and from other sectors that engage with people living with SUD including health care providers, behavioral health providers, criminal justice entities, and payors. Stakeholders could select how they self-identify from **15** stakeholder groups (or enter an “Other” category); the groups most represented by participants are:
  - **38.8%** SUD Treatment/Prevention Provider (n=451)
  - **25.7%** Behavioral Health Provider (n=299)
  - **20.4%** Friend or family member of someone with a history of SUD (n=237)
  - **13.1%** Advocate (n=152)
  - **13.1%** Person with lived experience with SUD (n=152)
  
- On average, over a decade of experience informed participants’ insights. The mean average length of experience living with SUD, familiarity with someone living with SUD, and/or providing services to people living with SUD was **~18 years**.
  
- Participants represent different types of communities: rural, suburban, and urban.

**Stakeholder Group.** As shown in Table 1, participants represent the variety of stakeholders who are affected by Pennsylvania’s SUD confidentiality policies. In addition to people with lived experience or those working in the SUD treatment field, participants include representatives from entities beyond DDAP’s purview. As described under the Methods section, broad participation was sought because Pennsylvania’s SUD confidentiality policies – like SUD itself - impact a broad cross-section of stakeholders beyond DDAP’s licensed providers.

**TABLE 1: Stakeholder Experience (n=1163)**

Stakeholder Group *	n	%
SUD Treatment/Prevention Provider	451	(38.8%)
Behavioral Health Provider	299	(25.7%)
Friend or family member of someone with a history of SUD	237	(20.4%)
Advocate	152	(13.1%)
Person with a history of/lived experience with SUD	152	(13.1%)
Community Based Organization	123	(10.6%)
Government Agency	116	(10.0%)
Single County Authority	113	(9.7%)
Health Care Provider/Clinician	92	(7.9%)
Probation/Parole Officer; Corrections	89	(7.7%)
Payer: Insurance; Managed Care Organization	77	(6.6%)
Hospital or Health System	63	(5.4%)
Research/Academia/Evaluation	29	(2.5%)
Certified Recovery Specialist/Peer Specialist	14	(1.2%)
Courts	12	(1.0%)
Case Manager/Care Coordinator	12	(1.0%)
Attorney/Counsel	9	(0.8%)
Trainer/Educator	9	(0.8%)
Other	4	(0.3%)
Professional/Trade Organization	3	(0.2%)
Children, Youth and Families (CYF) / Women, Infants and Children (WIC)	2	(0.1%)
Center of Excellence	1	(0.1%)
Recovery Homes	1	(0.1%)
Elected Official	1	(0.1%)

\* Participants could select more than one group to describe themselves.

**Years of Experience.** Years of experience with SUD could include personal, lived experience with SUD and/or professional experience providing treatment or services to people with SUD. Per Table 2, survey results represent a range of experience, from under one year to 60 years.

**TABLE 2: Type of Stakeholder Experience (n=1158)**

Years of Experience	n	%
0 to 4 years of experience	118	(10.2%)
5 – 9 years of experience	161	(13.9%)
10 – 14 years of experience	194	(16.8%)
15 – 19 years of experience	153	(13.2%)
20 – 24 years of experience	184	(15.9%)
25 – 29 years of experience	110	(9.5%)
30 – 34 years of experience	123	(10.6%)
35 – 39 years of experience	45	(3.9%)
40 – 44 years of experience	46	(4.0%)
45 – 49 years of experience	12	(1.0%)
50 – 54 years of experience	8	(.7%)
55 – 59 years of experience	2	(.2%)
60 – 64 years of experience	2	(.2%)

**Geographic Representation.** Per Table 3, survey participants represent the different types of communities in Pennsylvania. Multiple communities could mean a person represents an entity that works statewide or has sites in different types of communities. To keep the survey anonymous, participants were not asked to name their specific county or region of the state.

**TABLE 3: Geographic Representation (n=1159)**

Years of Experience *	n	%
City or Urban Areas	412	(35.5%)
Suburban Areas	172	(14.8%)
Rural Areas	236	(20.4%)
Multiple types of communities in Pennsylvania	304	(26.2%)
Communities in Pennsylvania and other states	33	(2.8%)
Community outside of Pennsylvania	2	(0.2%)

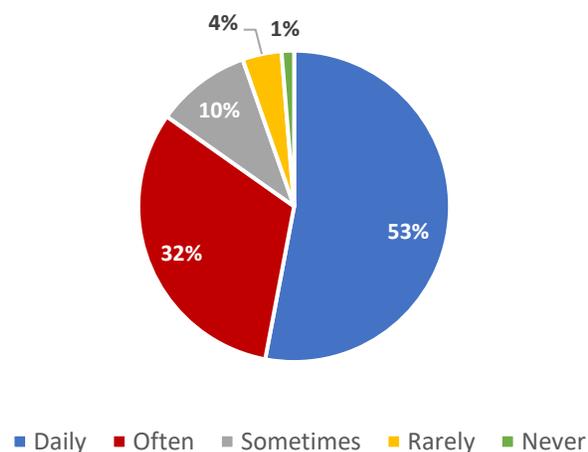
## Section Snapshot

### Experience with SUD Confidentiality Policies

- Survey participants have a strong understanding of Pennsylvania’s SUD confidentiality policies, grounded in frequent experience with them through their life and/or work.
- Most participants self-rank themselves as having an adequate to expert understanding of Pennsylvania’s SUD confidentiality policies.
- Participants experience the confidentiality policies from a diversity of viewpoints: people whose personal information is being shared, SUD providers managing the flow of data, and partner entities trying to obtain data.

**Frequency.** Per Figure 2, most respondents – 84.8% (n=981) - report that SUD confidentiality policies come up frequently in their life or work (daily or often/a few times a month).

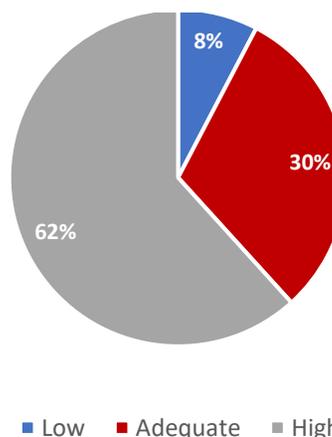
**Figure 1: How frequently do Pennsylvania’s SUD confidentiality policies come up in your life or work? (n=1157)**



**Expertise.** Per Figure 2, most respondents – 92.3% (n=1071) - report that they have at least an adequate understanding of the SUD confidentiality requirements.

**Figure 2: How well do you feel like you understand Pennsylvania’s SUD confidentiality policies? (n=1160)**

- 61.7% High (n=716)
- 30.6% Adequate (n=355)
- 7.7% Low (n=89)



*High: ranked 8-10; Adequate: ranked 5-7; Low: ranked 1-4*

## Section Snapshot

### Benefits Associated with The Current Policies

- **60.7%** (n=646) of survey participants agree that the current policies encourage people to seek treatment because their privacy will be protected.
  - This was echoed in free text replies with participants describing how privacy and confidentiality are important to securing and maintaining clients’ trust in the treatment process.
    - This trust helps clients feel secure disclosing personal SUD information during the therapeutic process without fear that it will be used against them.
- **Protection** is the most cited benefit of Pennsylvania’s current policies in free-text replies. This includes protection from:
  - Stigma and discrimination,
  - Misuse of information, and
  - Punitive consequences, rather than support, for a person’s SUD.

The survey asked participants to rate whether they agreed with certain commonly cited benefits of Pennsylvania’s SUD confidentiality policies (Table 4). Over half of all survey participants agree that the current policies:

- Encourage people to seek treatment because they know privacy will be protected.
- Keep client in control of own records.
- Protect client from adverse actions by employer.

Over half of all survey participants disagree that “there are no benefits to the current policies.”

**Table 4: Stakeholder-Rated Benefits of Pennsylvania’s Current SUD Confidentiality Policies (n=1067)**

Benefits of Current Requirements	Disagree Strongly or Disagree (%)	Undecided (%)	Agree or Agree Strongly (%)
<b><i>A plurality of participants agree that the current policies:</i></b>			
Encourage people to seek treatment because they know privacy will be protected	253 (23.7%)	167 (15.7%)	<b>646 (60.7%)</b>
Keep client in control of own records	251 (23.5%)	202 (18.9%)	<b>612 (57.4%)</b>
Protect client from adverse actions by employer	204 (19.1%)	249 (23.3%)	<b>612 (57.4%)</b>
Protect client from criminal prosecution	304 (28.5%)	284 (26.6%)	<b>473 (44.3%)</b>
Limit data to prevent service denials or reduction of insurance benefits	358 (33.6%)	274 (25.7%)	<b>428 (40.1%)</b>
<b><i>A plurality of participants disagree that the current policies:</i></b>			
Protect client from loss of child custody	<b>404 (37.9%)</b>	393 (36.8%)	266 (24.9%)
Protect the client from stigma	<b>437 (41.0%)</b>	197 (18.5%)	426 (39.9%)
Have no benefits	<b>598 (56.0%)</b>	258 (24.2%)	198 (18.6%)

When asked if there were additional benefits of Pennsylvania's current policies, 215 people provided feedback. Of these, 57.2% (n=123) described benefits in their own words. Most of these responses reiterated benefits listed in Table 4 (n=83). Other themes described how Pennsylvania's state-specific policies benefit people living with SUD by:

- Providing general overall protection (n=16)
- Protecting the client from entities other than the ones described in Table 4 (n=15)
- Protecting the client from multiple entities (n=9)

The responses had a few common subthemes.

- The current policies also benefit people living with SUD by:
  - Fostering honesty and openness among clients in treatment.
  - Ensuring privacy in treatment.
  - Helping SUD treatment providers protect the client.
  - Protecting clients from judgement.
- Some stakeholders expressed support for the current policies because:
  - Collaboration among providers is possible under the current policies.
  - They fear that changing Pennsylvania's policies will cause harm.

Appendix C includes a table summarizing key themes and subthemes, including challenges that were also described in the free text replies.

## Section Snapshot

### Challenges Associated with The Current Policies

- A majority of participants agree with statements describing how Pennsylvania’s policies make it challenging to share a person’s data, even with consent and even when the intent of sharing might benefit a person living with SUD.
  - **79.5%** agree they lead to exclusion of SUD from client records, giving an incomplete client history.
  - **67.4%** agree they are too restrictive about which entities can receive data.
  - **60.5%** agree they make it difficult to integrate SUD services in health care settings.
  - **50.5%** agree they make it difficult to evaluate programs and improve services.
- More than half of all survey participants agree that Pennsylvania’s policies are not fully protecting people living with SUD from possible harms.
  - **55.1%** agree they perpetuate stigma by keeping SUD data separate from other health information.
  - **53.8%** agree they do not fully prevent negative consequences.
- Issues related to **coordination, collaboration, and integration** of services for people living with SUD are the most cited challenge of Pennsylvania’s current policies in free-text replies.
  - Stakeholders described how Pennsylvania’s specific limits on what pieces of information can be shared and with whom create barriers that prevent entities from providing help to people living with SUD.

The survey asked participants to rate whether they agree with certain commonly cited challenges of Pennsylvania’s SUD confidentiality policies (Table 5). Over half of all survey participants agree that the current policies:

- Lead to the exclusion of SUD from client records, leaving providers with an incomplete client history.
- Are too restrictive about which entities can receive data, even with client consent.
- Make it difficult to integrate SUD services in health care settings.
- Perpetuate stigma by setting SUD apart from other health conditions.
- Do not fully prevent negative consequences (e.g., in areas of employment or child custody).
- Make it difficult to evaluate programs and improve services.

Over half of all survey participants disagree that the current policies “do not create any challenges or barriers.”

**Table 5: Stakeholder-Rated Challenges of Pennsylvania’s Current SUD Confidentiality Policies (n=1066)**

Barriers or Challenges of Current Policies	Disagree Strongly or Disagree (%)	Undecided (%)	Agree or Agree Strongly (%)
<b><i>A plurality of participants agree that the current policies:</i></b>			
Give providers an incomplete client history because of exclusion of SUD from client records	122 (11.4%)	131 (12.3%)	<b>809 (75.9%)</b>
Are too restrictive about which entities can receive data, even with client consent	238 (22.3%)	109 (10.2%)	<b>718 (67.4%)</b>
Make it difficult to integrate SUD services in health care settings	234 (21.9%)	185 (17.4%)	<b>645 (60.5%)</b>
Perpetuate stigma by setting SUD apart from other health conditions	273 (25.6%)	199 (18.7%)	<b>587 (55.1%)</b>
Do not fully prevent negative consequences (e.g., in areas of employment or child custody)	174 (16.4%)	315 (29.5%)	<b>574 (53.8%)</b>
Make it difficult to evaluate programs and improve services	287 (27%)	234 (22%)	<b>539 (50.5%)</b>
Do not fully protect clients from criminal prosecution	186 (17.4%)	371 (34.8%)	<b>501 (47%)</b>
Make it difficult to obtain insurance authorization for treatment	327 (30.7%)	268 (25.1%)	<b>471 (44.2%)</b>
They prevent expansion of SUD treatment	36 (33.4%)	296 (27.8%)	<b>407 (38.2%)</b>
<b><i>A plurality of participants disagree that the current policies:</i></b>			
Create no challenges	<b>808 (75.8%)</b>	159 (14.9%)	81 (7.6%)

When asked if there were additional challenges of Pennsylvania’s current policies, 302 people provided feedback. Of these, 75.8% (n=229) described challenges in their own words. Slightly more than half of these responses reiterated benefits listed in Table 5 (n=121). Additional themes in these replies described how Pennsylvania’s state-specific policies pose a challenge to people living with SUD by:

- Limiting care coordination and service integration (n=38)
- Impeding SUD treatment access or continuity of care (n=30)
- Being broadly too restrictive (n=21)
- Posing specific issues related to children and families (n=19)

Common subthemes added more detail about the challenges. Stakeholders described how people living with SUD are affected by the current policies because they:

- Limit a client’s control of their own record, including in cases where they want to share their progress.
- Limit providers when they are trying to help or advocate for their clients.
- Foster mistrust between systems and perpetuate siloes of care.
- Prohibit the disclosure of certain information which could lead to assumptions that could harm client ("guilt" by omission).
- Create redundancies that are an inefficient use of resources.
- Hinder Pennsylvania’s response to the overdose crisis by making it difficult to initiate multifaceted, cross-sector responses to overdoses and SUD (ex: warm handoff programs).
- Stymie progress because outdated policies do not reflect changes in the SUD landscape like new treatment options or entry points into treatment.
- Make the process of exchanging client information burdensome and/or time consuming for both clients and the entities serving them.
- Create a chilling effect around the use of any SUD data.
- Challenge record sharing among entities in different states.

A more detailed table in Appendix C summarizes all the key themes and subthemes, including benefits that were also described in the free text replies.

## Section Snapshot

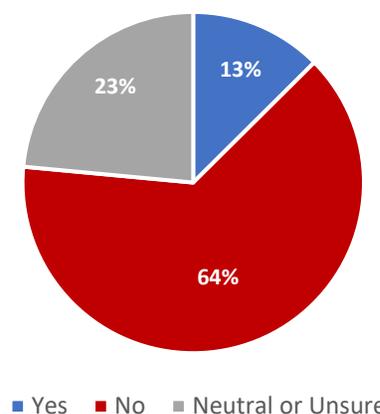
### Does Pennsylvania need policies above and beyond Federal Regulations?

- **63.9%** of survey participants think Pennsylvania does not need SUD confidentiality policies that go above and beyond federal confidentiality regulations.
  - In most stakeholder groups, over 50% of participants do not feel that Pennsylvania needs confidentiality policies that go above and beyond federal regulations.
- While a plurality of advocates and people with a history of/lived experience with SUD also do not think that Pennsylvania needs to have confidentiality policies that go above and beyond federal regulations, a greater number of people in these groups are unsure or support state specific policies than other stakeholder groups.
- **54.9%** of 255 additional comments describe challenges with the current policies or support for changing Pennsylvania’s policies.

Pennsylvania is one of only three states that has SUD confidentiality policies that go above and beyond the federal SUD confidentiality requirements established in 42 CFR Part 2. Stakeholders were asked to reflect on whether Pennsylvania needs policies that are more restrictive.

Per **Figure 3**, most survey participants – 63.9% (n=677) - do not feel that Pennsylvania needs policies that go above and beyond federal privacy regulations.

**Figure 3: Do you think it is necessary for Pennsylvania’s SUD confidentiality requirements to be more restrictive than federal regulations? (n=1059)**



In most stakeholder categories, over half of participants in each category do not think Pennsylvania needs more restrictive policies. Per Table 6, there are three groups where less than half agree that Pennsylvania does not need policies above and beyond federal regulations: advocates, people with a history or lived experience with SUD and peer recovery specialists. While a plurality of these groups said “No”, these groups were more unsure or in support of state specific policies than other groups.

**TABLE 6: Are there differences in how stakeholder groups replied to whether Pennsylvania needs state-specific SUD confidentiality policies that go above and beyond federal regulations? (n=1059\*)**

Stakeholder Category *	Does PA need more restrictive SUD confidentiality policies than federal policies?			
	Yes (%)	No (%)	Not Sure (%)	Total
Hospital or Health System	3 (5%)	50 (83%)	7 (12%)	60
Probation/Parole Officer; Corrections	2 (3%)	64 (82%)	12 (15%)	78
Case Manager/Care Coordinator	-	8 (80%)	2 (20%)	10
Payer: Insurance; Managed Care Organizations	2 (3%)	58 (79%)	13 (18%)	73
Government Agency	9 (9%)	74 (70%)	22 (21%)	105
Behavioral Health Provider	33 (12%)	186 (68%)	54 (20%)	273
Courts	-	8 (67%)	4 (33%)	12
Health Care Provider/Clinician	3 (4%)	56 (66%)	26 (31%)	85
Research/Academia/Evaluation	4 (17%)	15 (63%)	5 (21%)	24
SUD Treatment/Prevention Provider	68 (16%)	258 (62%)	93 (22%)	419
Single County Authority	17 (16%)	60 (56%)	30 (28%)	107
Community Based Organization	17 (15%)	61 (55%)	32 (29%)	110
Friend or family member of someone with a history of SUD	38 (18%)	116 (54%)	62 (29%)	216
Advocate	29 (21%)	68 (49%)	43 (31%)	140
Person with a history of/lived experience with SUD	38 (28%)	54 (40%)	44 (32%)	136
Certified Recovery Specialist/Peer Specialist	4 (36%)	2 (18%)	5 (45%)	11

\* Participants could select more than one stakeholder category to describe themselves.

Participants were given space to elaborate on their position; key themes were pulled from these free text responses. Of the 255 additional thoughts provided:

- 39.6% (n=101) describe how Pennsylvania’s current policies are challenging because they:
  - Impede care and/or coordination of services for client (n=31)
  - Are not needed because federal regulations are sufficient (n=29)
  - Are confusing, burdensome, and/or too restrictive (n=26)
  - Can harm clients or do more harm than good (n=9)
  - Have not evolved to reflect changes in the field and beyond (n=6)
- 19.6% (n=50) support keeping Pennsylvania’s state-specific policies because they:
  - Feel that federal policies are not protective enough (n=20)
  - Think Pennsylvania-specific policies are needed to protect clients (n=20)
  - Support the current policies or can describe benefits to Pennsylvania’s policies (n=10)
- 15.3% (n=39) support changing state-specific policies to align with federal confidentiality regulations
- 14.1% (n=36) support keeping state-specific confidentiality policies but with modifications:
  - Support changes to help improve treatment access or coordination of care (n=22)
  - Support some changes but also agree with components of current policies (n=10)
  - Keep Pennsylvania’s policies but provide more clarity and education. (n=4)

The remaining 29 responses did not fit into the above categories.

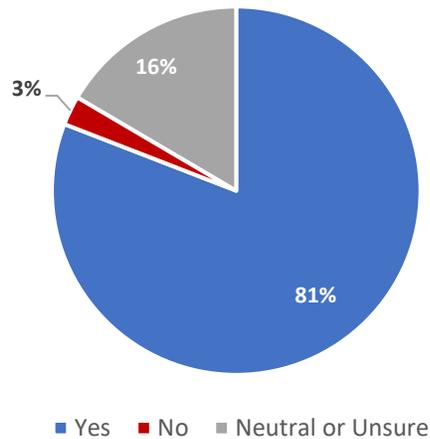
## Section Snapshot

### Can Pennsylvania's SUD confidentiality policies be improved?

- **80.9%** of survey participants think Pennsylvania's SUD confidentiality policies can be improved.
  - In every stakeholder group, most participants agree these policies can be improved.
- Participants selected their preferred options for improving Pennsylvania's policies, the top three were:
  - **58.5%** Revise requirements to account for updates to the field and make requirements clearer and more well-defined (n=577)
  - **57.2%** Develop guidance materials to clarify requirements (n=564)
  - **48.2%** Revise requirements to align with federal regulations (42 CFR Part 2) (n=476)
- Only **5%** of participants think there should be no changes made to Pennsylvania's current policies.

A majority of survey participants – 80.9% (n=817) - believe Pennsylvania's SUD confidentiality policies can be improved.

**Figure 4: Do you think Pennsylvania's current SUD confidentiality policies can be improved? (n=1010)**



Replies to this question were broken down by type of stakeholder. Table 7 shows that in every stakeholder group, the majority of participants agree that Pennsylvania’s policies can be improved (this table is limited to stakeholder groups with over 10 respondents).

For the most part, less than 5% of respondents in all stakeholder groups do not think the policies can be improved.

In two categories of stakeholders - people with a history of/lived experience with SUD and certified recovery specialists or peer specialists – slightly more than 25% of respondents are unsure if the policies could be improved.

**TABLE 7: Are there differences in how stakeholder groups replied to whether Pennsylvania’s SUD confidentiality policies can be improved? (n=1010\*)**

Stakeholder Group *	Can PA’s SUD confidentiality policies be improved?			
	Yes (%)	No (%)	Not Sure (%)	Total
SUD Treatment/Prevention Provider	325 (81%)	12 (3%)	66 (16%)	403
Behavioral Health Provider	214 (82%)	3 (1%)	44 (17%)	261
Friend or family member of someone with a history of SUD	168 (82%)	6 (3%)	32 (16%)	206
Advocate	102 (76%)	5 (4%)	28 (21%)	135
Person with a history of/lived experience with SUD	92 (71%)	4 (3%)	33 (26%)	129
Community Based Organization	85 (83%)	2 (2%)	15 (15%)	102
Single County Authority	77 (78%)	1 (1%)	21 (21%)	99
Government Agency	81 (84%)	3 (3%)	12 (13%)	96
Health Care Provider/Clinician	72 (89%)	-	9 (11%)	81
Probation/Parole Officer; Corrections	64 (85%)	-	11 (15%)	75
Payer: Insurance; Managed Care Organizations	71 (97%)	-	2 (3%)	73
Hospital or Health System	54 (86%)	1 (2%)	3 (5%)	63
Research/Academia/Evaluation	19 (86%)	-	3 (14%)	22
Certified Recovery Specialist/Peer Specialist	8 (73%)	-	3 (27%)	11
Courts	9 (82%)	1 (9%)	1 (9%)	11
Case Manager/Care Coordinator	9 (90%)	1 (10%)	-	10

\* Participants could select more than one stakeholder group to describe themselves.

Stakeholders were asked to select up to three specific strategies they think could improve Pennsylvania’s policies, with options developed some suggestions in a [2019 George Washington report](#) about these policies. Options for improving them, ranked by the number of participants who preferred each option are:

- 58.5% Revise policies to account for updates to the field; make policies clearer, more well-defined (n=577)
- 57.2% Develop guidance materials to clarify policies (n=564)
- 48.2% Revise policies to align with federal regulations (42 CFR Part 2) (n=476)
- 14.4% Other: Elaborated or provided other options (n=142)
- 6.9% Revise policies to add more SUD confidentiality protections (n=68)
- 5% Do not make any changes to the current confidentiality policies (n=49)

An “Other” category was also included for people to write in additional strategies that may not have been included in this list; 142 respondents entered additional thoughts about improving Pennsylvania’s SUD confidentiality policies.

- 64.8% (n=92) support changing or revising Pennsylvania’s policies. In addition to elaborating on the listed options, participants also expressed the desire to:
  - Improve sharing of data and client information to help people living with SUD (n=17)
  - Improve communication and collaboration between entities serving people living with SUD (n=14)
  - Remove restrictions on what data clients can share or which entities can receive a person's record/data with a client’s consent (n=8)
- 17.6% (n=25) have cautious or mixed feelings towards changing or revising Pennsylvania’s policies. In addition to elaborating on the listed options, participants also expressed the desire to:
  - Improve training and education around SUD confidentiality (n=9)
  - Concern about compliance with current SUD confidentiality policies (n=3)
- 3.2% (n=16) oppose changes or revisions to Pennsylvania’s policies.

The rest were miscellaneous replies that do not fit into any of the above categories. Several subthemes cut across key theme areas and elaborate on specific improvements stakeholders want to see made or describe reasons why they feel changing policies would improve care for people living with SUD:

- Address electronic records and digital data sharing.
- Allow clients to provide verbal consent, particularly when telemedicine is being initiated.
- Certain entities would like more specific client information to protect wellness of a larger unit (ex: employers/workplace, families).
- Client should have more control over their own record and care.
- Encourage collaboration and coordination between SUD, behavioral health and medical providers.
- Improve coordination of care for people with co-occurring conditions (ex: mental health & SUD).
- Address inconsistent guidance on current policies.
- Streamline the client consent process.
- SUD confidentiality should be like medical and/or mental health confidentiality.

## Section Snapshot

### How could aligning Pennsylvania's policies with federal regulations improve care for people living with SUD?

- Over 300 participants think care for people living with SUD would be improved if Pennsylvania's policies are updated to align with federal regulations.
- Most responses envision improvements that would make coordination of services and collaboration and communication between providers easier.
- Participants also think alignment will make confidentiality clearer which will improve compliance with confidentiality policies.

Given that all but three states – Pennsylvania, Kansas and Oklahoma – align with federal SUD confidentiality regulations, the survey sought to understand what stakeholders thought could be the best- and worst-case scenarios if Pennsylvania moves towards alignment with federal regulations.

39.2% (n=497) of survey participants provided thoughts about whether harmonization with federal regulations could improve care to people with SUD. Of these, 72.8% (n=362) of replies described possible ways care might be improved by:

- Making it easier to provide support to clients through expansion of coordinated care, integrated SUD services, and communication between a client's providers (n=130)
- Providing clarity which would improve consistency and compliance with confidentiality policies (n=89)
- Improving the sharing of data and client information, with a client's consent (n=42)
- Improving care generally (n=41)
- Improving entry into SUD treatment and streamlining a client's movement through the SUD treatment continuum (n=23)
- Improving cross-state care coordination (n=21)
- Improving the process of authorization for insurance and other benefits (n=16)

Of the remaining responses:

- 15.7% described uncertainty towards alignment or their response did not fit in other categories (n=78)
- 8.7% described concerns about challenges or issues for people living with SUD (n=43)
- 2.8% described mixed feelings about alignment (n=14)

Subthemes that cut across these areas described more specific ways care might be improved if Pennsylvania aligns its SUD confidentiality policies with the federal regulations:

**Table 8: Subthemes describing possible improvements if Pennsylvania’s SUD confidentiality policies align with federal regulations.**

<b>Client level improvements</b>	<ul style="list-style-type: none"> <li>• Clients would:             <ul style="list-style-type: none"> <li>○ Be more active participants in their own care</li> <li>○ Have more autonomy and control over their own records</li> <li>○ Have more choice in their treatment decisions</li> </ul> </li> <li>• Ease client stress and reduce burden on clients in exchange of records</li> <li>• Improve client safety</li> <li>• Remove barriers to care and improve continuity of care</li> <li>• Improve quality of care for clients</li> <li>• Informed client consent would still be needed to share information and communicate about client</li> <li>• Providers can better advocate for clients with more information</li> </ul>
<b>SUD treatment improvements</b>	<ul style="list-style-type: none"> <li>• Greater transparency</li> <li>• Creates more standardization</li> <li>• Will help with ASAM implementation</li> <li>• More efficient; would allow for more time for treatment</li> <li>• More information will help determine best treatment option for a client</li> <li>• More information will help providers offer more client-centered care</li> <li>• Care will be more comprehensive</li> </ul>
<b>Cross-systems improvements:</b>	<ul style="list-style-type: none"> <li>• De-silo care and expand entry points for SUD care and services</li> <li>• Aligns with movement to treat SUD like a chronic health conditions</li> <li>• Allow for a more holistic, whole person approach to a person's care</li> <li>• Better address social determinants of health by helping collaboration between providers</li> <li>• Improve teamwork in multi-disciplinary settings (ex: treatment court)</li> <li>• Will be a more efficient use of state resources</li> <li>• More openness about SUD will help reduce stigma</li> <li>• Reduce confusion around confidentiality</li> <li>• Enhance research and evaluation</li> <li>• Sites could explore strategies to integrate care and better serve co-occurring conditions</li> <li>• Would align Pennsylvania with other states, providing consistency across state lines</li> </ul>

## Section Snapshot

### How could aligning Pennsylvania's policies with federal regulations challenge care for people living with SUD?

- Over **100** participants described ways care for people living with SUD might be challenged if Pennsylvania's policies are updated to align with federal regulations.
- Most responses express concerns that alignment could lead to people living with SUD being denied services or being exposed to harm including stigma or having their data misused.
- **170** participants responded to this question by stating they do not anticipate any challenges to clients if state policies align with federal regulations.

30.8% of survey participants (n=390) provided thoughts about whether harmonization with federal regulations could challenge care to people with SUD. Of these, 26.4% (n=103) of replies describe possible ways care might be challenged because:

- Clients might:
  - Not seek care or receive the care they need (n=21)
  - Not be as open or share as much information (n=15)
  - Be more exposed to stigma and/or discrimination (n=11)
- Client data could get out or be misused beyond what a person consents to share (n=19)
- It would generally be bad or bad for the clients (n=15)
- It could create more restrictions and/or barriers to care and treatment (n=12)
- Legal or criminal justice entities could have access to more data (n=10)

Of the remaining responses about challenges that might occur if Pennsylvania policies aligned with federal regulations:

- 43.6% do not anticipate challenges (n=170)
- 18.2% described uncertainty about alignment or provided a reply that did not fit into other categories (n=71)
- 11.8% described mixed feelings about alignment (n=46)

Subthemes that cut across these areas describe more specific ways care might be challenged if Pennsylvania aligns its SUD confidentiality requirements with the federal regulations:

**Table 9: Subthemes describing possible challenges if Pennsylvania’s SUD confidentiality policies align with federal regulations.**

<p><b>Client level challenges:</b></p>	<ul style="list-style-type: none"> <li>• Concern that clients will be:               <ul style="list-style-type: none"> <li>○ Afraid to seek treatment</li> <li>○ Less likely to share information with providers</li> </ul> </li> <li>• Some clients prefer more restrictive guidelines</li> <li>• Clients would not trust their information would be protected</li> <li>• Concern clients will not have informed consent over how their data is used</li> </ul>
<p><b>SUD treatment challenges:</b></p>	<ul style="list-style-type: none"> <li>• Changes could have a negative impact on therapeutic relationship</li> <li>• It would be an adjustment for providers and/or clients to get used to changes to the policies</li> <li>• Will need to train providers on revised policies</li> <li>• Would need to improve trainings:               <ul style="list-style-type: none"> <li>○ How to prevent data breaches</li> <li>○ Informed consent</li> </ul> </li> </ul>
<p><b>Cross-systems challenges:</b></p>	<ul style="list-style-type: none"> <li>• Mistrust of other systems to provide quality care to people living with SUD</li> <li>• Mistrust of other systems to protect client data</li> <li>• Perception that confidentiality will be weakened</li> <li>• Fear a client's SUD history will be used against them</li> </ul>

## DISCUSSION

### Why Is Pennsylvania Talking About SUD Confidentiality...Again?

In 2008, the Pennsylvania Department of Health (which then housed Drug and Alcohol Programs) proposed changes to 4 Pa. Code § 255.5 because, “regulations relating to disclosure of client-oriented information have become outdated and an impediment to service delivery and the coordination of care for individuals with substance abuse problems.”<sup>xv</sup> More than a decade later, DDAP and other state agencies continue to hear from stakeholders that these issues persist. But they also hear from stakeholders who oppose changing SUD confidentiality policies because of fears about stigma and other consequences for people living with SUD.

Per the Project Background, in 2019 DDAP brought on a designated staff to collect stakeholder feedback on the issue of SUD confidentiality policies. Interest in seeing Pennsylvania leaders address this issue is evidenced in the eager response from stakeholders: over one thousand people took time to complete the online survey and seventy people shared in-depth insight in interviews.

While Pennsylvania’s SUD confidentiality policies specifically regulate DDAP-licensed SUD treatment providers, many other stakeholders find their work entangled in these policies. The breadth of stakeholders who participated in the survey speaks to this complexity. As described in the Results, survey activities captured a variety of stakeholder experiences and attitudes. Findings confirm that Pennsylvania’s SUD confidentiality policies continue to be a source of conflict and confusion for stakeholders. Specifically, the results catalog:

- Why stakeholders support or oppose changes to Pennsylvania’s policies.
- How specifically stakeholders want to see Pennsylvania’s policies change.
- What are hopes or concerns if changes were to be made to Pennsylvania’s policies.

In reviewing these findings, policymakers must consider the questions asked of stakeholders in this report:

- Do current SUD confidentiality policies – and/or the perceptions of these policies – affect access to care for people who are enrolled in or in need of SUD services in Pennsylvania?
- How can Pennsylvania address challenges and concerns with SUD confidentiality policies in a way that maximizes benefits to people in need of SUD services and minimizes harm while protecting client data?

Most survey replies reflect optimism that making changes to Pennsylvania’s SUD confidentiality policies will help expand and enhance SUD services by improving coordination and integration among health and social services. While the confidentiality of people living with SUD is seen as important, so is people’s autonomy to self-determine which entities can access their treatment records. Attempts to keep SUD in a silo by maintaining the status quo not only ignores a shift towards integration in the allied health fields, but risks putting Pennsylvania at a disadvantage in its efforts to address SUD and prevent overdose fatalities.

There was a tone of urgency in stakeholders’ findings, which reflects the urgency of recent headlines. Early projections for 2020 indicate Pennsylvania may see an increase from 2019 in lives lost from overdose. At the heart of the replies described in this report and its stakeholder-informed recommendations is a desire to make SUD care, treatment, and support more accessible to people living with SUD throughout Pennsylvania.

## Key Themes from Stakeholder Feedback

Stakeholders who participated see this subject as important to the future of SUD service provision in Pennsylvania, regardless of whether the participant is in favor of keeping Pennsylvania's SUD confidentiality policies in place or if they are advocating for these policies to change. Below is a summary of major themes that emerged, particularly in the free text survey replies and interviews, when participants provided more detailed reflections on SUD confidentiality in Pennsylvania.

*Direct quotes from survey and interview participants are italicized.*

### **People living with SUD do not have full control over their own SUD treatment record.**

Whether stakeholders are in favor of changing Pennsylvania's policies or not, there is agreement that people living with SUD should receive individualized, person-centered care. In that spirit, clients of SUD services should be able to determine for themselves which entities can access their SUD record(s). Yet, it is Pennsylvania's SUD confidentiality policies that mandate what information is sufficient for release rather than the client in partnership with their providers.

Currently, even when a person consents to share their record, Pennsylvania's SUD confidentiality policies limit what pieces of information can be shared with certain entities.

- *“DDAP seems to be the one perpetuating the stigma, rather than accepting the attitude of empowering patients to determine when, how and to whom their private substance abuse information can and should be shared.”*

Pennsylvania's policies perpetuate an idea that people living with SUD are not able to decide for themselves who can have access to their SUD records and denies them control over their own SUD record.

### **Updating Pennsylvania's policies will expand support and services for people living with SUD by making it easier to coordinate care, integrate SUD services, and communicate between systems and providers.**

Stakeholders report that having a set of state-specific policies – in addition to federal policies - makes SUD record sharing confusing, inefficient, and burdensome. Pennsylvania's policies have not been modernized to reflect changes affecting confidentiality more broadly such as HIPAA, electronic medical records, or the move toward health care integration.

Clients' privacy should not be sacrificed solely to make data sharing easier for the systems that serve them; but stakeholders pointed out that clients also benefit when their records can be shared more efficiently (presuming the parties exchanging records comply with federal privacy policies). The most cited barriers associated with Pennsylvania's policies relate to their impact on helping people living with SUD navigate between systems and providers. Lags in the transfer of client information can negatively affect a person's continuity of care.

Providers describe ways Pennsylvania's policies hinder coordination of care between different providers by:

- Excluding SUD from electronic medical records and health information exchanges, preventing providers from having a holistic picture of their clients.
  - *“The current regulations get in the way of providers seamlessly sharing information as is necessary to support the delivery of quality care to patients. The regulations fly in the face of current federal*

- efforts to electronically share information. They also fail to take into consideration that providers need to understand the totality of a patient's conditions in order to deliver quality care."*
- Discouraging communication between providers or forcing providers to use "workarounds" to share information, putting them at risk for violation of the policies.
    - *"It truly affects the communication between programs that are working hard to provide assistance to the client. All of the agencies are working to help a client become self-sufficient, but when we can't work together, it creates duplication and overlapping from multiple agencies. We need one universal release, so that clients are able to access all programs that may be helpful to get a client back on his/her feet again. It is very frustrating when a client gives permission to access their information through D&A, D&A still says the information cannot be released due to confidentiality laws."*
  - Keeping SUD treatment in a silo by impeding integrated care; health systems and other entities are hesitant to offer or expand SUD services because of concerns about the burden of compliance with Pennsylvania's policies.
    - *"Providers, including mental health, primary care and drug and alcohol providers, find it difficult to access information about past treatment and care which impedes safe, informed treatment planning, coordination and integration of care. By increasing the discretion and power of the individual to direct the sharing of all information to a designated recipient from his or her drug and alcohol related record, Pennsylvania would promote the provision of coordinated and integrated treatment of drug and alcohol and/or co-occurring disorders in an efficient and potentially life-saving manner."*

Some stakeholders express frustration about the contradiction of being told by state agencies to improve interoperability and integration but find it difficult to do so because of Pennsylvania's policies.

- *"Allow more simple integration with medical services/records. Also, get all agencies on the same page because there is too much contradiction and confusion between DDAP, SAMHSA, state agencies, etc."*
- *"The State is increasingly interested in the integration between physical health and behavioral health and not being able to discuss SUD leaves out a big part of a patient's care. Physicians are prescribing medications and making treatment recommendations without a full picture of a patient's needs."*

This confusion can make it challenging for entities to meet service goals and quality improvement deliverables.

### **Changing policies should not be interpreted as removing confidentiality.**

Stakeholders agree that confidentiality and privacy are important for building the trust of people living with SUD so that they feel safe entering treatment. In treatment, people disclose very personal information. People should not be harmed when seeking help so regulating confidentiality and emphasizing the importance of data protection helps clients as well as the reputation of the SUD treatment system.

While state policies may change, client confidentiality is not being removed, despite this fear among a small subset of stakeholders.

- *"Counselors will no longer be able to say that the patient's information is truly confidential. In fact, counselors meeting patients for the first time will have to disclose that private information is no longer confidential. A terrible way to start a counseling relationship."*

Just because there may no longer be restrictions on what specific pieces of information can be shared with certain entities does not mean that a person's SUD treatment information will no longer be confidential. Data held by a SUD treatment provider will still be protected by federal privacy protections including Part 2 and HIPAA. A client's consent will still be required in most cases for their information to be shared with any entities beyond the SUD treatment provider.<sup>4</sup> Furthermore, a person will still have the right to revoke their consent at any time.

- *"The client would still need to sign an ROI [Release of Information] for the information to be released. This leaves the information that can be divulged completely up to the client and that is the person's personal decision, not the state's."*

Proponents of change describe good intentions behind their support to reform SUD confidentiality policies but people living with SUD have valid reasons to opt out of sharing their SUD records. People living with SUD have experienced stigma and discrimination in many of the systems that purport to help them and some of these systems have historically harmed more than they have helped people.

Providing clients with sufficient information to make informed decisions to share their records, honoring their decision to share their records (or not) and maintaining data securely is critical to building and maintaining the trust of people living with SUD.

- *"Individuals often are not aware of the potential ramifications of disclosure. Providers often do not spend the time necessary to adequately discuss the pros and cons of disclosure. The regulations recognize that disclosure can harm clients and provides needed protection. I am appalled at the failure of other providers to discuss how one can be harmed by disclosure. In medical settings, I have never experienced as a recipient anything close to informed consent when asked to provide consent for disclosure."*

Some stakeholders point out that even the current policies do not fully eliminate the risks of sharing personal records. This suggests the benefits of the current policies offer marginal protection to people living with SUD at the cost of limiting clients' control of their own records and preventing opportunities to share information in ways that could help living people living with SUD.

- *"It's like saying no one should keep money in a bank because it might get robbed."*

## Stakeholders Want to Know the Benefits of Change Will Outweigh the Harms

### **There is more uncertainty about change than opposition to change.**

Sixteen percent (16%) of participants are neutral or unsure if Pennsylvania's policies can be improved; compared to 3% who do not think they can be improved and 80.9% who believe they can be improved. Per Table 7 in the Results section, the stakeholders that are most likely to be unsure about whether Pennsylvania's policies can be improved are: people with a history of/lived experience with SUD, advocates, and Single County Authorities.

Since Pennsylvania has had its policies in place for almost fifty years, most people with experience in SUD treatment have only known these policies. For stakeholders who can see both pros and cons of the current policies, it can be hard to choose between keeping the familiar, despite its challenges, or making change and risking uncertainty:

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<sup>4</sup> Under Part 2 there are some exceptions when providers can make a disclosure without a person's written consent: internal communications, medical emergencies, reports of alleged child abuse or neglect (per state law), reports of a crime on premises or against program personnel, qualified audits or evaluations of the program, research, or qualified service organization agreement.

- *“I feel that substance abuse disorder confidentiality requirements should be more restrictive in some areas but should not in others. It needs to be re-looked at to ensure that these laws are not providing more strain and less of an opportunity to make sure our clients are getting the appropriate help.”*

Based on surveys and interviews, much of the concern stems from uncertainty about what confidentiality protections will remain. There is confusion or lack of clarity on the interplay of different state and federal SUD confidentiality policies and policies in intersecting areas such as physical and behavioral health. Given this, it is no surprise that over half of survey participants (58.5%) agree that Pennsylvania’s policies could be improved by revising them to be clearer and more well-defined.

People also want to know with certainty that if Pennsylvania’s policies are changed, people living with SUD will be protected. If more information can be shared by changing policies, stakeholders have a valid concern about whether unintended consequences may result in harm to people living with SUD, particularly in the form of stigma, discrimination, or having a person’s SUD record be used against them.

### **Some stakeholders are concerned Pennsylvania could miss opportunities to prevent overdoses.**

As the scope of the SUD and overdose crises have grown, more resources have become available to target these issues in different ways, often using a multidisciplinary team approach. As funding streams to address these issues come from more diverse sources, project deliverables are coming into conflict with Pennsylvania’s SUD confidentiality policies. Specific examples described by stakeholders include:

- **Overdose Fatality Review (OFR) teams.** These initiatives seek to collect data about overdose fatalities to help local, state, and national policymakers better understand gaps and missed opportunities to improve services and better target resources to prevent overdose deaths. Teams obtain signed releases of information from decedents’ next of kin and each OFR has its own confidentiality and non-disclosure agreements in place among participants. Getting release of information for client records from some OFR partners can be difficult because of Pennsylvania’s policies. One partner told an OFR coordinator, *“We really love what you are doing, but we are afraid of the legal ramifications if we share this data.”*
- **Warm Handoff programs.** A county wanted to conduct an evaluation of local warm handoff programs to 1) assess whether people were following through with referrals to services and 2) use this information for quality improvement. Consent would be obtained from clients who participate in a warm handoff in an emergency department which would grant designated officials’ permission to match client-identifiers to Medicaid claims in order to assess effectiveness of these programs. The county’s counsel was concerned this project would violate 71 P.S. § 1690.108 and did not permit the evaluation to proceed.
  - *“It would be helpful if the law clearly gives treatment and healthcare providers some leeway to communicate for the purposes of referring to treatment and following up on referrals. It can be a challenge to have clients give written permissions for these purposes when, for example, a client calls and says that they decided to go to rehab and are asking for providers to help find beds.”*

Stakeholders cite examples of partner agencies withholding records from these initiatives out of concern that participating would put them in violation of Pennsylvania’s SUD confidentiality policies. This raises concern that incomplete data could jeopardize outcomes of efforts to prevent overdose fatalities.

### **Many stakeholders think Pennsylvania’s policies perpetuate stigma rather than protect from stigma.**

There was agreement in interviews that Pennsylvania cannot regulate its way out of stigma but disagreement over whether changing confidentiality policies would help or hinder efforts to reduce stigma. Pennsylvania’s SUD

confidentiality policies mandate segregation, rather than integration, of a person's SUD care and treatment records. This sends a mixed message to providers and clients of SUD services:

- *"We say, treat it like a disease, people shouldn't be ashamed, but instill fear and demand secrecy."*
- *"The longer substance use disorders remain more private than other medical conditions, they will continue to be stigmatized more than other disorders. We are constantly telling patients that substance use disorders are no different from other medical conditions like diabetes or hypertension but we keep the treatment of substance use disorders secret, we are perpetuating the stigmatization of substance use disorders. As a health care community we need to get substance use disorders out in the open so we can more readily identify, treat, and normalize the disorder."*

Advocates who would prefer to keep a person's SUD diagnosis or treatment record separated - for example, from the rest of a medical or mental health record - want to protect people living with SUD from stigma and discrimination. Inclusion of SUD diagnosis or treatment in a record could put clients at harm for discrimination, a very real and valid concern. Even as other fields are trying to provide more and better services to help people living with SUD, there are people working in these fields who may - because of their own personal bias and judgement - treat someone differently if they see a history of SUD in a person's record (this line of thinking suggests an assumption that stigma and discrimination are absent from or are less likely to occur in SUD treatment spaces).

Stakeholders outside DDAP's SUD system who work with people living with SUD are pleading for changes to Pennsylvania's confidentiality policies because they want to play a role in supporting people in need of SUD treatment and support. Stakeholders that would like more access to SUD records also bear a responsibility to create safe spaces for people to be transparent about their SUD history. Retaining clients in care is dependent on their trust that they can share their history without being judged.

## Does More Regulation Protect Pennsylvanians Better Than Other States?

Pennsylvania's laws governing disclosure of SUD treatment information date to the 1970s and therefore they reflect the health care system as it existed nearly fifty years ago. Since that time, federal confidentiality protections have been introduced and revised: the HIPAA Privacy and Security Rules went into effect in 2000 and 2003, respectively; 42 CFR Part 2 dates from the 1970s but was revised in 2017 and 2020 to better align with HIPAA.

Today, Pennsylvania is the only state in the nation that places restrictions on the type of information that may be disclosed and the people or entities who may receive that information, regardless of whether a person consents to having more information shared.<sup>xvi</sup> In all but two other states (Oklahoma and Kansas), the disclosure of SUD records with a client consent aligns with 42 CFR Part 2.

The original intent of Pennsylvania's policies, which pre-date federal confidentiality regulations, meant to ensure people living with SUD felt safe entering treatment. Proponents of Pennsylvania's policies appreciate that they are customized to the needs of our state and feel they add an extra layer of protection that benefits clients of SUD treatment.

- *"Federal regulations are specifically broad to meet the needs of states across the country. Pennsylvania's regulations are tailored to meet the needs of our specific system. I see great value in that."*

But many stakeholders question why it is still necessary for Pennsylvania to have its own policies when most other states consider federal privacy policies sufficient. Some stakeholders even note how the absence of information

because of Pennsylvania’s restrictions can be used against a client. Individuals or facilities that have experience across state lines offer a perspective on how working in Pennsylvania compares to other states:

- *“I have worked in other states where they follow the federal guidelines and there is better collaboration, less stigma and more access to the appropriate and applicable resources. PA regulations are a hindrance to integration, create more stigma and make it very hard to even include care givers, at times parents into the understanding of and the sharing of treatment plans, follow ups, etc.”*
- *“I worked in other states for years. The other states are able to provide comprehensive and competent treatment without the extra hoops to jump through. It honestly usually creates more barriers than anything else.”*

It is important to note that additional changes to Part 2 are expected to be introduced for public comment in 2021.<sup>xvii</sup> Some stakeholders are reluctant to see Pennsylvania’s policies change now, while federal policies are still in flux.

## Confidentiality Intersects with Other Structural Challenges

Updating SUD confidentiality policies alone will not help reduce overdose deaths and increase access to SUD treatment. One interview participant worries that the focus on, *“changing confidentiality regulations keeps us from bigger systemic changes.”* That is a fair critique, and it is worth closing this report by noting other big picture issues stakeholders mention; these must also be addressed to improve access to services for people living with SUD and ensure that Pennsylvanians have access to an integrated, state-of-the-art, well-funded SUD treatment system.

- **Streamline Pennsylvania regulations more broadly to facilitate expansion of integrated care models.** Service providers making the effort to offer comprehensive wraparound services to clients should be supported in doing so but the regulatory environment can make it challenging as several state agencies oversee different components of care and regulation of care. As systems become more integrated and multi-disciplinary, state agencies should work together to streamline Pennsylvania’s complex and intersecting regulations. Commonwealth agencies that are providing intersecting services should collaborate – amongst each other and with community partners - to identify challenges to service integration and develop strategies to make health and social services more accessible and easier to navigate for Pennsylvanians seeking help – in particular, residents with co-occurring health, SUD, and behavioral health issues.
  - *“I believe that the mental health and substance use confidentiality regulations need to be more in tune with the current healthcare situation and instead of being separate, consider integrating them. The substance use regulations are outdated and make it very difficult for agencies who deal with both mental health and substance use to share information with others to get the best treatment for patients.”*
- **Improve use of data in the SUD field to monitor and enhance quality of services.** Some stakeholders are frustrated that limits on data sharing between stakeholders prevents innovation that could benefit people living with SUD. Stakeholders want to improve access to client-centered approaches such as evidence-based treatment, multidisciplinary disease management models, and using electronic health records or health exchanges to target people who might benefit from interventions (for example, to address overdose risks).
  - *As long as confidentiality policies prohibit personal identification the rest of the data can be used to improve programs and services and individualize treatment in more meaningful ways. Not having a full history for an individual struggling with SUD can make it difficult to know the best fit of service/support for the client.*

- **Criminalization of drug use puts clients at risk of punishment when support is needed.** Judges and probation/parole officers are included on the list of restricted entities under Section 255.5 because advocates for people living with SUD do not want a person’s treatment information to be used against them in a criminal justice setting. While the criminal justice/legal system is evolving through initiatives like treatment court or diversion programs, there are still many cases where a punitive approach is applied in cases involving someone with SUD. Is the solution to this to continue to use 255.5 to protect people, or address the legal statutes that criminalize addiction?
  - *“I would like to see [individuals] treated more for SUD than criminalized and their kids taken from them with the stigma that they are bad people.”*

## Closing Considerations

There is strong agreement across stakeholder groups that Pennsylvania’s SUD confidentiality policies should be modernized and improved.

While reviewing the recommendations outlined in this report, policymakers should consider risks, particularly the risk of changes to people living with SUD. The main concerns cited by stakeholders in surveys and interviews include:

- **Educating and informing stakeholders.** Any changes to the policies must be accompanied by activities to educate stakeholders about the changes. Whereas providers currently can withhold information based on Pennsylvania’s policies, changes would make the release of information more centered on what each client is comfortable releasing. Clients of SUD treatment should receive clear information about their rights regarding their records. As such, training and education on policy changes should include a skill building component to support SUD providers in helping clients make informed decisions about releasing their information.
- **Data security.** Protecting client privacy is essential to maintain trust in the security of SUD treatment. There is a valid concern that allowing certain entities to have greater access to a person’s SUD record will increase the risk that sensitive information disclosed in SUD treatment could be exposed. However, many stakeholders feel clients should be the ones to decide for themselves if the release is worth the risk, rather than having state policies make this decision for them.
- **Coercion and data misuse.** Proponents of the current policies believe they are still necessary because of concern that without these protections, certain entities would coerce individuals into releasing information they are not comfortable sharing. Furthermore, there is concern that these entities may use information against someone rather than use it to help them (ex: insurers denying SUD treatment coverage, employers firing someone for a history of SUD).
- **Stigma and discrimination.** As with data breaches, Pennsylvania’s SUD confidentiality policies do not prevent stigma and discrimination but attempt to reduce the risk to people living with SUD by limiting what information can be shared. While stigma towards addiction is changing, it still exists and can still cause significant harm to people living with SUD. Despite well-meaning stakeholders who would like SUD data to be more accessible to help people, there are still providers and systems that see a history of SUD in someone’s record and treat them differently or penalize them for having a medical condition. As has been reiterated in this report, systems that seek more access to a person’s SUD record must be proactive in helping to address stigma in these systems. In the replies, some stakeholders describe how it could be empowering to give people living with SUD control over their own record.

Pennsylvania’s SUD confidentiality policies derived from good intentions to protect people living with SUD and make people feel secure entering treatment for SUD. But a lot has changed since the 1970s, many stakeholders argue,

and Pennsylvania's policies need to be updated to reflect how attitudes towards and services for people living with SUD have evolved. Some even go so far as to say Pennsylvania's policies now do more harm than good by perpetuating denial of services, fragmented care, and limiting client autonomy. While some risks exist, most stakeholders see positive benefits to change that will ultimately help improve services for people living with SUD:

- **Improve care coordination, collaboration, and integration.** While in theory the current policies should not be a barrier to care coordination between SUD and healthcare providers, stakeholder responses to the survey indicate that the current policies can be so confusing that they often pose a barrier to efficient communication between providers. Stakeholders believe alignment with federal regulations will make SUD confidentiality clearer and make coordination between providers more efficient and streamlined for people navigating between several different providers.
- **Expand pathways into SUD care, treatment, and support.** Several stakeholders describe projects they want to introduce in their systems or jurisdictions to help link people to treatment, prevent overdose deaths, and improve partnerships between local providers. But these efforts are challenged by concerns about SUD confidentiality policies. When providers have so much fear about violating regulations that they avoid implementing or participating in initiatives to combat SUD and overdoses in their communities, Pennsylvania risks missing opportunities to save lives.
- **Enhance evaluation and use resources more efficiently.** Improving access to data and clarifying how data can be used may open more opportunities for research and analysis on service utilization, effectiveness of treatments, and provide opportunities for data-driven quality improvement.
- **Normalize SUD as a health issue and modernize the field of SUD.** As the view of SUD continues to evolve and more people and entities accept SUD as a treatable health condition, the state can encourage bridges between providers by modernizing confidentiality policies.

Proponents of the current policies offer a reminder that the convenience of providers should not trump the safety of people accessing SUD treatment. The feedback that the current policies are burdensome and inconvenient is not just a problem for providers, it is also a problem for clients, and it impacts their access to holistic, client-centered care. Having control of their record and deciding for themselves who they entrust to know more about their SUD history should be part of the individualized approach to whole person health care. In return, providers and entities who request access to SUD records should honor that trust by being transparent with clients about how the data will be used, stored, and protected.

The results of this survey reflect a genuine interest from health and social service providers to expand models that encourage healing and reduce harm. Some of these are systems where people with a history of substance use have and felt harmed and these systems must work to build trust with partners in the SUD community.

Systems and stakeholders advocating for SUD confidentiality policies to change need to play an active and ongoing role in dismantling stigma and discrimination simultaneous to building up their role in responding to Pennsylvania's SUD and overdose crises. Even if Pennsylvania's policies evolve to meet the needs of the time, confidentiality and consent protections will still be in place in some form because the intent of the original policies is still key: individuals entering SUD treatment have the right to privacy.

Confidentiality is just one piece of a complex system of services that people living with SUD navigate. As other sectors recognize their role in navigating people living with SUD through care, treatment, and support, confidentiality must be addressed to encourage expansion and integration of SUD services.

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- <sup>i</sup> OpenDataPA. Estimated Accidental and Undetermined Drug Overdose Deaths 2012 – Current. <https://data.pa.gov/Opioid-Related/Estimated-Accidental-and-Undetermined-Drug-Overdos/m3mg-va8e>. Accessed 2 February 2021.
- <sup>ii</sup> OpenDataPA. Opioid Data Dashboard: Estimated Number of Individuals with Drug Use Disorder. <https://data.pa.gov/stories/s/Pennsylvania-Opioids/9q45-nckt/> Accessed 7 June 2021.
- <sup>iii</sup> Centers for Disease Control and Prevention. *Drug Overdose Deaths*. <https://www.cdc.gov/drugoverdose/data/statedeaths.html>. Accessed 7 June 2021.
- <sup>iv</sup> US Senate Committee on Health, Education, Labor and Pensions. The Economic Cost of the Opioid Epidemic in Pennsylvania. <https://www.overdosefreepa.pitt.edu/wp-content/uploads/2018/10/The-Economic-Cost-of-the-Opioid-Epidemic-in-Pennsylvania.pdf>.
- <sup>v</sup> Centers for Disease Control and Prevention, Center for Preparedness and Response. Health Advisory: Increase in Fatal Drug Overdoses Across the United States Driven by Synthetic Opioids Before and During the COVID-19 Pandemic. 17 December 2020. <https://emergency.cdc.gov/han/2020/han00438.asp>
- <sup>vi</sup> US Department of Health and Human Services (HHS), Health Information Privacy. The HIPAA Privacy Rule. 10 December 2020. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>
- <sup>vii</sup> US Department of Health and Human Services (HHS). Fact Sheet: SAMHSA 42 CFR Part 2 Revised Rule. 13 July 2020. <https://www.hhs.gov/about/news/2020/07/13/fact-sheet-samhsa-42-cfr-part-2-revised-rule.html> .
- <sup>viii</sup> “Table 8: Historical Drug Control Funding, FY 2013 – 2022.” *National Drug Control Budget: FY 2022 Funding Highlights*. Office of National Drug Control Policy. May 2021. <https://www.whitehouse.gov/wp-content/uploads/2021/05/National-Drug-Control-Budget-FY-2022-Funding-Highlights.pdf>
- <sup>ix</sup> Volkow, N. “Addiction Should Be Treated, Not Penalized.” *Health Affairs* (blog), 27 April 2021. <https://www.healthaffairs.org/doi/10.1377/hblog20210421.168499/full/>
- <sup>x</sup> U.S. Department of Health and Human Services (HHS), Office of the Surgeon General. Facing Addiction in America: The Surgeon General’s Report on Alcohol, Drugs, and Health. Washington, DC: HHS, November 2016. <https://store.samhsa.gov/product/Facing-Addiction-in-America-The-Surgeon-General-s-Report-on-Alcohol-Drugs-and-Health-Full-Report/SMA16-4991>
- <sup>xi</sup> Health Information and the Law. *Disclosure of Substance Use Records with Patient Consent: 50 State Comparison*. Posted on 4 Oct 2019. <http://www.healthinfolaw.org/comparative-analysis/disclosure-substance-use-records-patient-consent-50-state-comparison-0>
- <sup>xii</sup> Proposed Rulemaking: Confidentiality of Patient Records and Information, 37 Pa.B. 6529 (Dec. 15, 2007). Available at: <https://www.pabulletin.com/secure/data/vol37/37-50/2307.html>
- <sup>xiii</sup> Wide-ranging online data for epidemiologic research (WONDER). Atlanta, GA: CDC, National Center for Health Statistics; 2020. Multiple Cause of Death Files, 1999-2018. <http://wonder.cdc.gov/mcd-icd10.html> Accessed 7 June 2021.
- <sup>xiv</sup> PA Dept of Drug and Alcohol Programs website. SUD Confidentiality. <https://www.ddap.pa.gov/Pages/SUD-Confidentiality.aspx>
- <sup>xv</sup> 5 Proposed Rulemaking: Confidentiality of Patient Records and Information, 37 Pa.B. 6529 (Dec. 15, 2007). Available at: <https://www.pabulletin.com/secure/data/vol37/37-50/2307.html>
- <sup>xvi</sup> Disclosure of Substance Use Records With Patient Consent: 50 State Comparison. George Washington University’s Hirsh Health Law and Policy Program. Available at: <http://www.healthinfolaw.org/comparative-analysis/disclosure-substance-use-records-patient-consent-50-state-comparison-0>
- <sup>xvii</sup> Substance Abuse and Mental Health Services Administration. “Statement of 42 CFR Part 2 Amendment Process.” 9 April 2021. <https://www.samhsa.gov/newsroom/statements/2021/42-cfr-part-2-amendments-process>