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# Trust in Healthcare and COVID-19 Vaccine Readiness Among Individuals with Substance Use Disorder

## About the Report

This report from the Addiction Policy Forum sheds light on the experiences of individuals currently using substances, receiving treatment for a substance use disorder, and/or in recovery from a substance use disorder during the pandemic, and attitudes around willingness to take a COVID-19 vaccine. Supported in part by the National Institute on Drug Abuse (NIDA), a part of the National Institutes of Health (NIH).

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# **Executive Summary**

The Addiction Policy Forum conducted interviews to better understand healthcare access and trust in healthcare providers, COVID-19 vaccine readiness, and the effects of the pandemic on treatment and recovery. Study participants included individuals with an active substance use disorder (SUD), in recovery from a SUD, or receiving treatment.

Interviews were conducted among our network of participants and survivors between September 14 and September 27, 2020. Eighty-seven SUD participants were interviewed (N=87), and responses were included in the analyses for this report.

## **Highlights Related to Vaccine Readiness:**

- Fifty-three percent (53%) of participants reported willingness to take a vaccine for COVID-19: 45% saying yes and another 8% willing to take the vaccine at a later date.
  - Seventy percent (70%) reported that requiring multiple vaccines would have no effect on their decision, while 20% reported they would be less likely to take the vaccines if multiple doses were required.
  - Seventy-nine percent (79%) report that method of administration has no effect on their decision to vaccinate, while 16% reported they would prefer nasal administration and 5% cited a preference for an injection.

- Sources of information used for health decisions used by participants included doctors and other healthcare providers (80%), family (17%) and TV/newspapers (13%).
- Trust in doctors and other healthcare providers fell from 79% before the pandemic began to 62%, while participants reporting that they had "no trust" in their healthcare providers increased from 8% to 16%. Uncertainty in comfort levels with healthcare providers also increased, from 13% to 22% since the pandemic began.

## Other Highlights:

- Two out of three study participants report that COVID-19 has had a negative impact on their substance use disorder (SUD) or recovery status (65%).
- Primary substance use disorder data were collected from all study participants, with alcohol use disorder as the most prevalent primary SUD (44%), followed by opioids (15%) and nicotine (15%).
- The most prevalent treatment and recovery services utilized by study participants were support group meetings (68%), followed by counseling (39%) and outpatient/intensive outpatient programs (38%).



# Methodology

This study included a total of 87 participants that self-identified as having an active substance use disorder (SUD), in recovery from a SUD and/or currently receiving SUD treatment. Quantitative and qualitative data were collected via one-on-one interviews with Addiction Policy Forum trained staff. Participation in the study was voluntary and no identifying information was included in this report. The information gathered as part of this project allows for a greater understanding of their experiences and opinions on addiction-related issues in the context of COVID-19, and gives voice to participants.

Data were collected from September 14, 2020 through September 27, 2020. Approval of all research protocols, instruments, and communication materials was obtained by the IntegReview IRB, an independent institutional review board. The study population comprises individuals over the age of 18 who had active substance use disorder (SUD), were in recovery from a SUD, or were receiving treatment for a SUD (not mutually exclusive).

#### **Data Collection**

An interview guide was developed to capture participants' willingness to receive a COVID-19 vaccine when one is available, as well as perspectives on how the COVID-19 pandemic has impacted their experiences with the healthcare system, addiction services, and personal wellbeing. Information was also gathered on participants' self-reported SUD history. The interviews were conducted virtually and lasted 15-45 minutes. Interviews were audio-recorded, and participants gave verbal informed consent prior to the start of the interview.

## Sample Interview Questions

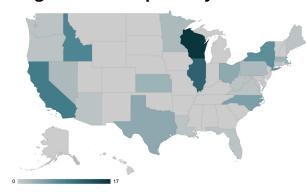
| Healthcare and addiction services prior to the pandemic   | Healthcare and addiction services during the pandemic  | Vaccine readiness   |
|---|--|---|
| What was your experience with the healthcare system and healthcare providers in the year prior to the   | Tell us about your experiences with healthcare during the pandemic, from March until now. (Follow up:  | Would you be willing to take a vaccine for COVID-19?  |
| pandemic? (Follow-up: Did you have routine healthcare visits or Emergency room or urgent care visits?)  | Have you seen a doctor, gone to the Emergency room or urgent care visits?)  During the pandemic have   | Does the method of administration, meaning an injection versus nasal spray, affect your decision to get vaccinated? |
| Did you feel comfortable with your doctors and have trust in them?  | you felt comfortable with your doctors and felt you could trust them?  |   |
| Can you share what type of addiction treatment and/or recovery services you are receiving/did you receive? (Follow-up: How often were you accessing these services, do you feel you | Have you accessed addiction or recovery services during the pandemic? (Follow-up: Have you felt trust in your addiction service providers?)  Has COVID-19 had an impact on your SUD and/or |   |
| have a trusting relationship with them?)  | recovery?  |   |

# **Demographics**

Of the 87 participants, 54% were female (n=47) and 46% male (n=40). Forty-one percent (41%) of study participants were in the 41-60 age group; 38% in the 26-40 age group; 13% in the 61 and older group; and 7% in the 18-25 age group.

| Demographics                     | N  |
|----------------------------------|----|
| Total Participants               | 87 |
| Gender Identity                  |    |
| Female                           | 47 |
| Male                             | 40 |
| Age                              |    |
| 18 - 25                          | 6  |
| 26 - 40                          | 33 |
| 41 - 60                          | 37 |
| 61 and Older                     | 11 |
| Race/Ethnicity                   | 1  |
| American Indian/Alaskan Native   | 8  |
| Black/African American           | 5  |
| Hispanic/Latino                  | 8  |
| Middle Eastern/North African     | 1  |
| Native Hawaiian/Pacific Islander | 2  |
| White/Non-Hispanic               | 63 |

Figure 1. Participants by State



The race and ethnicity breakdown of participants is as follows: 71% non-Hispanic White; 8% Hispanic; 8% Native American/Alaskan Native; 3% Black or African American; 1% Native Hawaiian/Pacific Islander; 1% Middle Eastern/North African; and 5% multiracial. Participants were from 21 states and the District of Columbia.

The study included individuals who have been diagnosed with a SUD, are in recovery, and/or have an active SUD. Participants were able to select multiple categories to describe their SUD history. Of the participants, 66 (76%) self-reported as being in recovery from a SUD, 16 (18%) reported currently using substances, 12 (14%) indicated they were currently receiving SUD treatment.

SUD history questions were included, and 80% reported polydrug use, meaning more than one substance of issue was reported, while 20% reported a single drug of concern.

Primary substance use disorder data were collected from all study participants, with alcohol use disorder as the most prevalent primary SUD (46%). This was followed by opioids (15%), nicotine (15%), stimulants (10%), multiple substances (10%), and marijuana (3%).



# **Vaccine Readiness**

Perspectives varied and concerns ranged from side effects to fear of rushed trials to stress over lack of reliable information. Several responses referenced to injections as potential triggers for individuals in recovery from a SUD: "Yes it would affect my decision- I was an IV drug user and injection is a huge trigger for me."

Fifty-three percent (53%) of participants reported willingness to take a vaccine for COVID-19: 45% saying yes and another 8% willing to take the vaccine at a later date. Reasons for the delay in receiving the vaccine included waiting for proper vetting and waiting to better understand side effects.

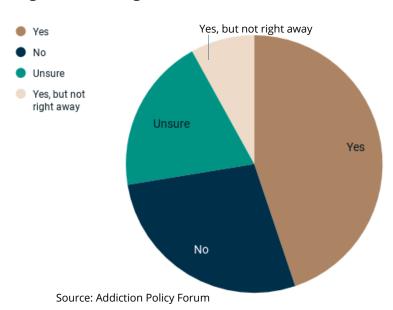


Figure 2. Willingness to Take a Vaccine for COVID-19

addictionpolicy.org

Seventy percent (70%) reported that requiring multiple vaccines would have no effect on their decision, while 20% reported they would be less likely to take the vaccines if multiple doses were required. Similarly, 79% reported that method of administration would have no effect on their decision to vaccinate, while 16% reported they would prefer nasal administration and 5% cited a preference for an injection.

Participants were also asked if they are concerned about being able to get the vaccine should they want it, with 69% not concerned and 26% reported concerns about access.

#### Perspectives - Vaccine Acceptance

"One thousand percent yes. I signed up for a trial though I have not been picked."

"I would, I guess who is administering it. I am open to it. It is the details and how it is presented. Right now, a lot of things are political so if it doesn't have the political tie to it then I would."

"Absolutely and looking forward to it."

"Yes, if my personal doctor recommends."

"Probably, would definitely do research first, not blindly taking it, make sure understands level of vaccine and what's involved, background in pharmacy." "I would definitely be willing to because I feel like technology advances are a lot better than they were years ago and COVID has really negatively affected my life."

"Yes. I would even be willing to participate in a study to test a vaccine."

"Yes, most definitely."

"Yes, but I wouldn't be the first."

## Vaccine Hesitancy

"Not immediately. No. We brought a lot of things to market too quickly, and I would have to ensure its safety prior to use."

"No, not a big believer in the COVID apocalypse, never gotten flu shot, no interest."

"I would not- I believe that I have already had [COVID] in back in February. It is not that I am against vaccines or with it but I don't get the flu vaccine. I had a weird chest cold that fit COVID symptoms."

"No. I would rather catch it; I don't trust the government. It's so new I don't want to be on the receiving end of it, I'm not high risk or anything, if I did catch it, I don't foresee it being fatal for me. I don't get flu vaccines."

"No, look at what we already know about COVID-19. We already know that COVID-19 is a coronavirus. It's highly unstable and can mutate very quickly. We've yet to produce a vaccine that's been even relatively successful at containing outbreaks of the common cold or the flu."

"No, don't trust vaccines to start. Don't trust doctors and scientist to make a decision because they contradict themselves. She also believes that it has been too rapid to find a vaccine and there won't be enough people studied before it comes out to know the long term effects."

"I'm really uncertain as to the short- or long-term efficacy of vaccination and it would take, in my view of good evidence-based practice, a very long period of vetting trials for human clinical trials and research to know what the shorter long term effects of those vaccines are. I have a number of co-occurring disorders. I have an autoimmune disease in addition to having a substance use disorder and a neurological disorder. So I'm very careful about what I introduced to my biology that could destabilize the very careful assembly of self-maintenance that I've been successful with."

"I'm really worried about the side effects and if it would actually work."

"I don't know. I think COVID is a real thing, and I had a friend die from it, but I don't think that the whole issue is as serious as this whole overreaction warranted. And I think I'll be fine; I've been fine so far. I've been exposed and I haven't come down with it. So, there's of course lack of trust in the government as well."

"I would say it depends. It would depend on when it came out, what studies backed up the effectiveness of it and which politicians endorse it."

"No, feel it's being too rushed, lots of vaccines have questionable ingredients, too risky, afraid it will be mandatory for child and don't want."

"No, I feel like it is such a new vaccine I wouldn't want to try it yet. I would want to see the results from it."



# **Trusted Sources of Health Information**

Sources of information for health decisions used by participants included doctors and other healthcare providers (80%), family (17%) and TV/newspapers (13%).

#### **Perspectives on Sources of Information**

## **Public Health Experts**

"CDC website, government sites, state sites are trustworthy, not social media. Dot gov means it's good."

"Science, CDC, national government healthcare also state and local agencies, central health district in Boise, value healthcare provider feedback, but not as much as national specialists."

"Not my doctor, don't like them, definitely not TV, social media gets bad rap but can find experts on twitter, trusts academics, government officials and experts."

## Personal Physician

"Social media God no. I trust my doctors. There are some independent new cast people that I watch. I don't trust the mainstream media to tell me whether it is raining so. Social media where every other person has a PhD in craziness including me."

"Definitely not social media. My doctor and my own research, because I will just simply research myself, and speaking with other people in my profession. I will always follow the science."

"Not social media. I do trust my doctors. I also do a lot of my own research- medical journals and I know who to ask if I have questions. I have a few MD friends that I can call or text. I use a combination of things- I prefer to read then to watch something or be told something on tv."

#### Multiple Expert Sources

"Never social media, rely on doctors primarily, trusted websites, .gov sites, majority of leaders speaking now, AMA, CDC, pediatric association, ACAD, governing boards and websites and talking points over media, also confirm with own doctors and nurse practitioners

"I guess a combination. Social media and the news may give me the idea and then I do my own research and run it by my doctor. I would say a combination and not one specific source. Again it sucks with everything being so political it is hard to find sources you can trust because both sides are saying something completely different and they're both supposed to be trusted sources."

## Friends/Family

"I kind of go by word of mouth. So like family or brothers or cousins. Um, I feel like there's a lot of like fake shit on the internet. So I don't really tend to read it. So word of mouth."

"I'm pretty fortunate that I have two cousins who work in healthcare, I have a cousin who is a PA and a cousin who works in public health, so I'd talk to them. I'm not saying I don't trust doctors, but I don't currently have a PCP. I'd also want to hear what Fauci says, I trust him."



# **Trust in Providers**

Seventy percent (70%) of participants reported accessing healthcare in the year prior to the pandemic and 58% reported positive experience with healthcare providers during that time. However, trust in doctors and other healthcare providers fell from 79% before the pandemic began to 62%, while participants reporting that they had "no trust" in their healthcare providers increased from 8% to 16%. Uncertainty in comfort levels with healthcare providers also increased, from 13% to 22% since the pandemic began.

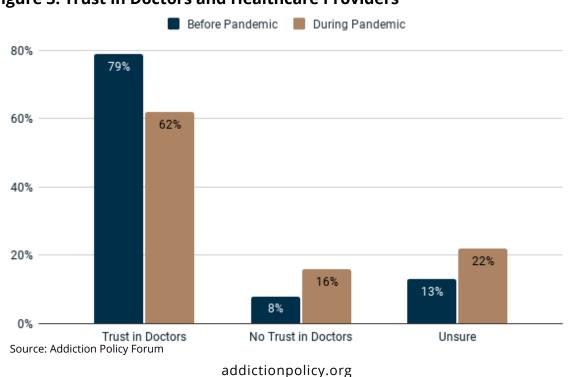


Figure 3. Trust in Doctors and Healthcare Providers

Similarly, trust and comfort levels with addiction service providers have changed slightly since the beginning of the pandemic. Only 6% of individuals reported distrust of their addiction services providers prior to the pandemic, compared to 9% during. Individuals who were not currently accessing services were categorized as "unknown".

Before Pandemic During Pandemic

40%

20%

Trust in Treatment and Recovery Services No Trust Not sure

**Figure 4. Trust in Addiction Service Providers** 

Source: Addiction Policy Forum

# Perspectives on Experience with Providers

## Experience with Providers During the Pandemic

"The doctors have all been really good, they've worn masks and been attentive to me as a patient and as careful as they can with COVID."

"Yes, of course. I have never felt I couldn't trust any medical provider."

"Yeah, I really like the doctor that I saw, so I trusted him."

"The providers in and of themselves, yes.
The meetings, since those aren't really
service providers...are just addicts - those
meetings I can't always trust because
everyone has differing opinions which need
to be respected."

"Lost trust in doctor because no mask and wouldn't provide testing."

"Less trust in my provider, was not taking COVID seriously until closures."

"Not at all, services were not accessible, agencies laid people off because lack of financial support, no replacing staffers."

"Yes; felt a little uneasy because there was a time a nurse called and said that her doctor wanted to know why she couldn't come in.- she didn't have transportation, medical cab- doesn't guarantee they would make a mask; she is super nervous and it's the unknown- don't know what to expect or what is going on"

"I don't trust him anymore because I don't feel like they care because I left messages that I was sick, and they haven't returned my call."

"Not really. They don't listen me."

"Yes, not that I don't trust my health care provider, but the last one I just saw - most of the rooms that you're in, when you're waiting for the doctor to come in - there's usually a sink and soap and all that and being that it is a pandemic and you would think that your doctor would want to put your mind at ease...when the doctor and staff came into the room, did not see him. he did not wash his hands, he did have a mask on, but then, as he's leaving, he just instinctively reached to shake my hand, so I shook his hand, and then he put his hand on my shoulder. I just thought it was very odd in the middle of a pandemic. I mean, I personally didn't mind because I just simply, as soon as he left, I washed my hands and did everything appropriately. But I felt like that was something he shouldn't have done, or when he first came into the room, he should have washed his hands and washed his hands as he was leaving the room so I could actually see him do that."

"I don't know if they're bad tests. They called [relative that got a COVID test] and they said positive and then they call it back to say the test is negative. Like, what's the point of even going if like it's going be like that."

#### Experience with Providers Prior t the Pandemic

"I definitely felt comfortable and trusted doctors."

"Yes, been through all of it with them, supportive, met where at, accepting."

"Generally speaking, [experiences with doctor] was fairly negative, I am also a type 1 diabetic, being strung out on meth it makes it hard to take care of yourself with diabetes. There were a couple occasions where it was necessary for me to seek medical attention at local emergency rooms where I felt like I was judged pretty harshly, and I was treated poorly by staff."

"Had a tough time, hard to see providers with no insurance, expensive."

"I would say I have mixed experience. I am searching for a new primary care physician right now because after my doctor left that clinic, I have had great medical care. I trust medical doctors generally. I trust the medical care system generally. I may not think that my doctors are genius. But generally speaking, I hold doctors in high regard and trust what they are saying provided that I am honest with them."

"Just standard healthcare regular visits before the pandemic. Yes, I was comfortable with the doctors."

"Yes, well my visits to the doctor, the place was clean, organized, I trusted the doctors and healthcare providers. I've went to the same place for several years and I do trust them."

"Not really. Had a doctor I didn't care. Got another doctor. Too many changes. Seemed like I was doing a lot of blood work all of the time."

"I very rarely would have went to the doctor. There was one time I had a bacterial infection and went to the hospital for that. I was open to what was going on, that it was from IV drug use. "The doctor was nice, and he treated me kindly. He shared that he was in recovery from substance abuse as well."



# Impact of COVID-19 Pandemic on SUD and Recovery

Two out of three participants report that COVID-19 has had a negative impact on their substance use disorder (SUD) or recovery (65%).

Comments on effects of the pandemic include concerns about impacts on recovery, access to recovery services, and the effects of isolation on mental health and SUD

"My biggest triggers are boredom and isolation, and so working from home and having to quarantine and isolate myself, it was just like, you know, like jumping into the lion's den."

## Perspectives on the Impact of COVID-19 on Recovery

## Negative Impacts on SUD/Recovery

"I relapsed four times during the pandemic and prior to that, I was sober for a year and a half. It's made it a lot more difficult to do the 12-step work because most of that type of stuff is done face to face with a sponsor and with COVID like we're not meeting face to face."

My bigger triggers are boredom and isolation, and so working from home and having to quarantine and isolate myself, it was just like, you know, like jumping into the lion's den."

"I have had a couple of slips and I believe it is due to the fact of routine change. Luckily, I work for an industry that is essential, but people could work from home- it brought a lot more stress to me because I was working in the office and it increased my job duties, length of workday, and then the stress. Then I would drive by liquor store and think it would just be once but then it would turn into a whole weekend."

"The pandemic absolutely has an impact on my recovery. All of the recovery meetings were shut down. Isolation for fear of the virus and increased mental health symptoms such as anxiety and panic attacks."

"Yes. It was depressing because I got laid off. There weren't meetings but I found comfort in friends and other activities."

"It's the reason I am back in counseling, community is disconnected from us because of COVID, has to be careful traveling due to his dad being high risk, can't go to church, isolation has been difficult, over consumption of information because not able to be out with people, trouble with depression and anxiety."

"Yes, Yes, Yes, in two ways. For a period of time it made me drink more than I normally would, and it also made me quit vaping because of the expense."

"Used more during pandemic."

"Definitely. It is a lot more difficult to hit up meetings because zoom is impersonal. It's a lot harder to reach out to new people, which is a big part of my recovery. Just because it is a lot harder to meet new people on zoom. It is a lot less interactive."

## Continuing Recovery During Pandemic

"It's definitely had an impact. I have not relapsed, but I have seen a lot of people relapse. I have seen definitely an uptick in overdose. It's been extremely difficult to not have physical contact with people I love and care about."

"Not a negative impact. 12 step is a fellowship where you join with other folks and background and you tend to lean on them like family. It is harder to establish that human touch because you're doing everything through a screen or phone call or text or email. it's like being long distance from a loved one. It's challenging but we're there for each other and we know we'll see each other down the road."

"It really hasn't changed much other than not meeting in person, we are just now meeting on the computer."

"I have been really blessed with family and my mental state of looking at things.

I have not struggled too bad during COVID. I was the type of addict that would find a reason to use. I have used this as a personal challenge- started running 5ks, became a peer support, and have used it as a growth period."

"I don't feel that it has had an impact on her substance use or recovery. It has been more stressful with social distancing, stores not open at the same time, lines, and other increases in stress levels, along with fear and isolation. I don't feel that it has affected my recovery because I have come so far to go back now."

"Thanks to meetings going to Zoom, no [have not relapsed]."

"Initially, I was in my head a lot like the first two months. A lot of roller coaster of emotions. But as far as I feel that I was very fortunate when the pandemic started because I had a very strong recovery foundation, I was plugged in all the right places, so as far as being fearful that I was going to use, that was never an option for me."

"I haven't thought about ... I have had a couple times when a drink sounded good but the next moment thinking through- drinking dreams and more smoking dreams; had to fight the temptation to buy a pack of cigarettes (stopped smoking 2 years ago); affected me more mentally and emotionally- I have allowed it to get me not very grounded or centered; I was doing too much and got zoomed out then I went back to if I don't do enough I am going to be a hot mess to people; it can go hand in hand because I have several dual diagnosis problems; it can rear its ugly head; being honest with my sponsor, other people, my therapist; do whatever I can to help someone else and stay more grounded because if I don't I just unwind and cause problems around me; the fear is the biggest thing and when this is going to happen or be near wreaking how can I feel safe; I don't have as many cravings to drink but more to smoke; I can't imagine getting sober during."



# **Experience with Telehealth During the COVID-19 Pandemic**

Prior to the pandemic, study participants varied in frequency of services accessed. Forty-two percent (42%) reported using services/programs multiple times per week, 32% reported no services used, 17% reported weekly access and 6% reported use of services monthly, while 4% reported annual access.

While utilization of treatment and services continued during the pandemic, participants expressed dissatisfaction with remote and modified options.

Multiple times per week

No utilization

Weekly

Yearly

0 10 20 30 40

Figure 5. Frequency of Service Access Prior to the Pandemic

Source: Addiction Policy Forum

# Perspectives on Telehealth

"Thanks to meetings going to Zoom, no [have not relapsed]."

"[Modified services are] most difficult part of pandemic."

"...It is a lot more difficult to hit up meetings because zoom is impersonal. It's a lot harder to reach out to new people, which is a big part of my recovery. Just because it is a lot harder to meet new people on zoom. It is a lot less interactive."

"... It is harder to establish that human touch because you're doing everything through a screen or phone call or text or email. it's like being long distance from a loved one. It's challenging but we're there for each other and we know we'll see each other down the road."

"Over the phone counseling, saw doctor once a month, urinalysis tests (only one person allowed at a time), 12 steps program, and online zoom meetings, and I have participated in webinar (getting ADAC). I have been able to attend ethics and boundaries course, recovery coach train the trainer course. Since COVID-19 it has made it easier to access these things because it is all on Zoom. It has its pros and cons. I have been able to get a lot of credits that involve recovery in general."

"It's different with Zoom. I don't feel as personal because with Zoom you can hide your picture. And then it's like you don't know and worry about confidentiality and anonymity, because it's Zoom you can't see people, they can hide themselves."

"Several meetings that I went to had Zoom bombers. There were people that came into the room, they said racial slurs, they put profanity on the screens. Not a lot but in the beginning a lot of the meetings were getting Zoom bombed really bad. And people were coming through and it doesn't make you feel safe."

"Someone told me to be careful when I'm on Zoom because I had a diploma behind me. They told me you need to turn that diploma over because they said that people can figure out who you are. That made me a little bit more paranoid. They also said, especially if you're zooming and you're outside and someone sees your house number, you've got to be careful. So that made me feel a little bit not as safe. So it's a little bit different. I don't feel as safe. It's different because when you're in an in-person meeting, you don't have to worry about that. But on Zoom you have people that are cyber savvy. It's not good."

"Meetings just started back up in my area, the counseling services were all shut down because it is in an inpatient treatment facility and didn't offer any telehealth services (they also shut down intensive outpatient too). I did some Zoom AA meetings online but it got uncomfortable because of Zoom bombers (people who are drunk or high or inappropriate) take away from the meeting. I use my apps alongside with my counselor and sponsor. For new people in recovery, like myself, it didn't work well for me to have my routine changed."

"Two coping skills groups through Zoom; last week started tai chi in person outside or in gymnasium social distant; all AA meetings are on Zoom; became a peer support during COVID in Wisconsin."

"I guess as much as possible. Everything has been a lot harder online than in person and it took a lot of adjusting for a lot of people."

"All of our treatment services have like been all over zoom. So I've been attending AA more. AA was through Zoom but now they are starting to open back up. I prefer in person treatment or any services like AA or counseling in person but now that it has opened back up. I'm no longer doing zoom, which is better."

"It really hasn't changed much other than not meeting in person, we are just now meeting on the computer."

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## About the Addiction Policy Forum

The vision at the Addiction Policy Forum is to eliminate addiction as a major health problem by translating the science of addiction and bringing all stakeholders to the table. The organization works to elevate awareness around substance use disorders and help patients and families in crisis. Founded in 2015, Addiction Policy Forum empowers patients and families to bring innovative responses to their communities and end stigma through science and learning.



