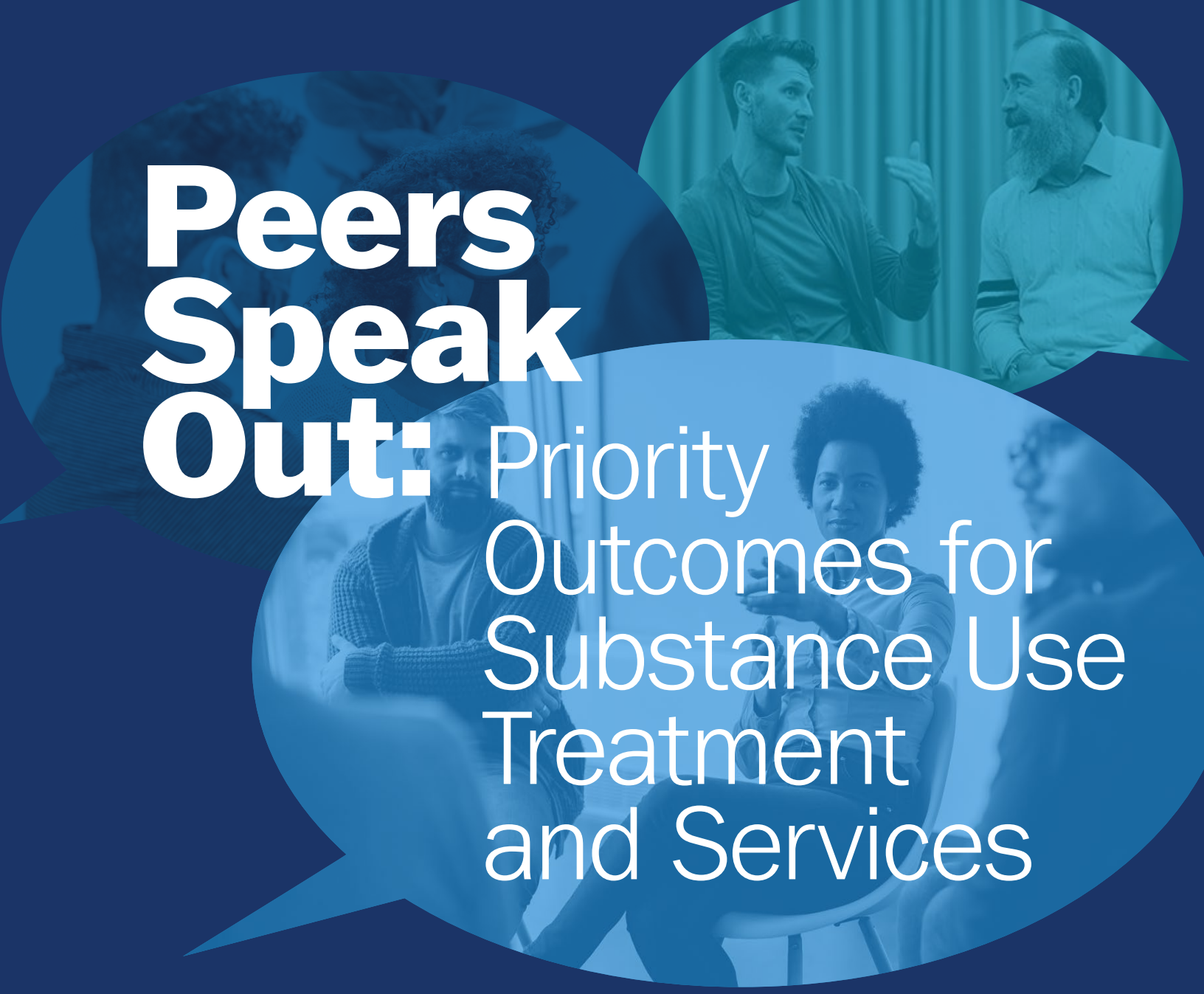

Peers Speak Out: Priority Outcomes for Substance Use Treatment and Services

APRIL 2021

Community Catalyst

FACES & VOICES OF RECOVERY
ADVOCATE. ACT. ADVANCE.

ASAM American Society of Addiction Medicine

Acknowledgements

NATIONAL PEER COUNCIL

The National Peer Council established through this project has been the grounding force to inform, guide and shape project activities. The project team is grateful to the council members for their commitment to this project, and the work they do every day improving the lives of people living with substance use disorders. We thank them for sharing their leadership, expertise, time, energy and experiences. This project would not have been possible without them and their thoughtful engagement.

- Brandi M. Vore, Site Manager, Oklahoma Citizen Advocates for Recovery and Transformation Association-OCARTA
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- Evan Done, Development Director, Utah Support Advocates for Recovery Awareness
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- Nathan L. Mitchell, Outreach Director, The McShin Foundation
- Tara Moreno-Wallen, Founder & Executive Director, The Serenity House of Flint
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Additional acknowledgements are in the Appendix.

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The views, statements, opinions presented in this report are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

I. Executive Summary

WHAT THIS PROJECT ADDS:

This is the first national examination of treatment outcomes prioritized by people with substance use disorders. The findings show individuals most care about survival, improving their quality of life and mental health, reducing harmful substance use, meeting their basic needs, increasing their self-confidence, and increasing their connection to ongoing services and supports. These broad expectations provide direction for reshaping research, services and policies to more effectively address the national epidemic of substance use disorders. Priority outcomes also differ across race and gender demographics, emphasizing the need for individually tailored, culturally and linguistically effective treatment and services, and the need to acknowledge and address structural inequities.

WHY THIS PROJECT MATTERS:

More than 20 million Americans have substance use disorders, and overdose deaths are rising. Too often, people with lived experiences of substance use disorders are left out of important policy decisions that affect their lives, including how treatment and recovery programs are designed and what outcomes those programs seek to achieve. This means that research on what works best often isn't focused on what matters most to people with addiction, resulting in services that aren't always responsive to individuals' needs and don't achieve the best results.

THE PROJECT GOAL:

Patients Lead aims to identify what outcomes matter most to people with substance use disorders to ensure their voices guide future research and action to improve the system.

The ultimate goal of the project is to improve treatment outcomes by focusing research, policymaking and service delivery on what people with substance use disorders want and need.

WHAT WE LEARNED:

After engaging 882 individuals with lived experience of substance use disorders across the country, Patients Lead learned that the outcomes from treatment and recovery support services[1] that matter most to individuals are:

1. **Staying alive**
2. **Improving quality of life**
3. **Reducing harmful substance use**
4. **Improving mental health**
5. **Meeting their basic needs**
6. **Increasing self-confidence/self-efficacy**
7. **Increasing connection to services and supports**

During COVID-19, the majority of respondents want the same top results as they did prior to the pandemic. For the 20 percent of people who prioritized different outcomes during COVID-19, quality of life became less important while connection to recovery support services, and taking care of basic needs, became more important.

These priority outcomes reflect the broad expectations people have for treatment ensuring their survival and improving their lives, and the lesser priority they place on completely stopping all drug and alcohol use. The results also highlight differences in priority outcomes across different

1 In this report, "recovery support services" includes peer recovery support services, housing supports, and other non-clinical recovery services and supports.

demographics. For example, 25 percent of white respondents selected "stop all drug and alcohol use" as a top priority compared to 13 percent of multiracial respondents. Also, 59 percent of transgender/nonbinary respondents[2] selected "stay alive" as a priority outcome compared to 26 percent of women.

Amid a period of national reckoning on racial injustice, COVID-19 has laid bare the racism in the health system, as those who already face unequal and discriminatory treatment continue to be hit hardest. Meanwhile, drug overdoses are increasing and addiction continues to be criminalized, especially among Black and brown communities. The project findings demonstrate the need to reshape research, services and policies to achieve patient priorities as part of larger efforts to address structural inequities. The findings also indicate the importance of providers understanding individuals' treatment and recovery goals, and providing culturally and linguistically effective services tailored to the person's desired outcomes and intersecting identities.

WHAT WE RECOMMEND:

We recommend policymakers, service providers, and patient-centered outcomes researchers focus on the outcomes that Patients Lead project participants prioritized and take action to improve addiction treatment. Our specific recommendations include:

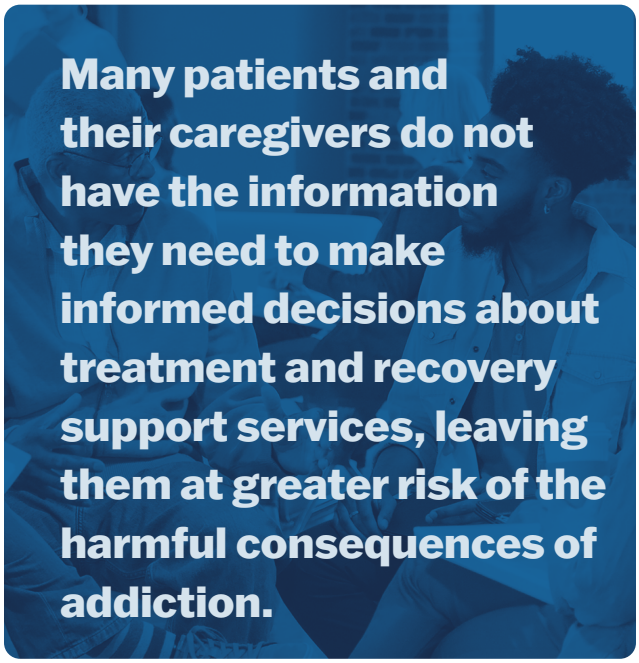
- *For policymakers:* Increase funding for the full continuum of services, from prevention and early intervention, including harm reduction and crisis services, to inpatient and outpatient treatment, to residential services and long-term peer recovery supports, including those provided by recovery community organizations. Target funding for harm reduction programs that focus on keeping individuals alive and reducing self-harm, for example overdose prevention and syringe services; also, fund provider education on harm reduction.
- *For services providers:* Clarify each individual's desired treatment and recovery goals and adjust services to meet those goals. Integrate mental health supports into substance use disorders services even for individuals without a documented mental illness diagnosis.
- *For researchers:* Investigate which treatment and recovery support services, including peer services, best achieve the outcomes patients want. Stratify all comparative effective research (CER) and patient-centered outcomes research (PCOR) related to substance use disorders by race/ethnicity and gender, and report findings by these demographics to inform clinical and non-clinical recommendations and policy solutions that address systemic inequities.

If you would like additional information about this report, please contact the project team at: TreatmentResults@communitycatalyst.org

2 Note: This is based on a relatively small sample as 17 survey respondents were transgender/nonbinary.

II. Background of the Problem

Our nation's rising drug overdose deaths and increase in overall substance misuse is spurring demand for treatment as well as the troubling growth of poor quality or fraudulent services. The need for quality substance use treatment and services is imperative, now more than ever. Data from the Centers for Disease Control and Prevention shows that overdose deaths are at an all-time high, with 88,000 deaths due to overdose in a 12-month period. A nationwide survey of more than 1,000 people with substance use disorders found that 20 percent reported their or a family member's substance use increased since the start of the COVID-19 pandemic. An analysis of a nationwide sample of 500,000 urine tests showed an increase in use of drugs such as cocaine, heroin, methamphetamine, and non-prescribed fentanyl.



Evidence-based treatment works, and the American Society of Addiction Medicine (ASAM) has defined Standards of Care and a full continuum of services. But the quality of treatment and recovery support services varies. Some programs are fraudulent, offering brokers payments for sending them patients and providing little or no treatment, or conducting unnecessary tests for an insurance payout. Sometimes programs charge inflated fees without providing good quality care. One study showed that of the people who receive treatment for addiction, very few receive evidence-based care.

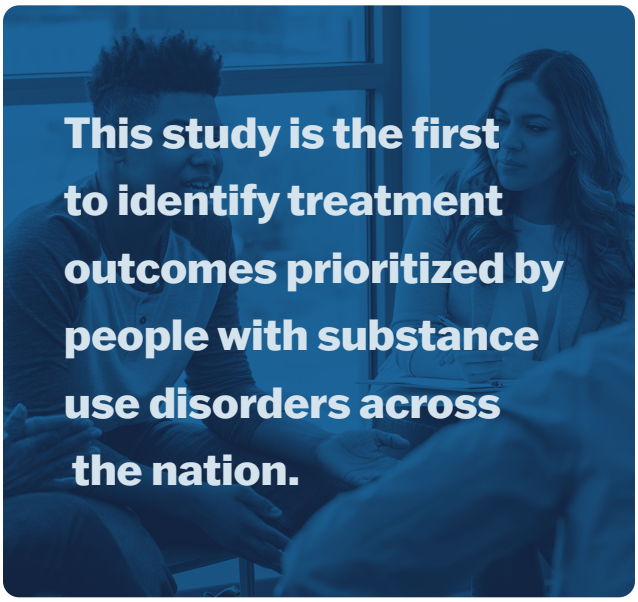
Furthermore, access to treatment is limited. The National Survey on Drug Use and Health estimates that in 2019 roughly one-fifth of people 18 and older with substance use disorders received any treatment. Moreover, COVID-19 has upended treatment and services for people with substance use disorders. Some treatment/recovery providers closed, while others have moved to mostly or entirely remote or virtual operations. This is a major disruption in a service delivery model that is built on face-to-face engagement. The shift has left some people without their support network, and some states have cut their addiction services budget to cover COVID-19 related costs. At the same time, changes in federal and state policies are permitting an unprecedented expansion in services provided by audio or audiovisual telephone, and availability of take-home medications. But providers, patient advocates and patients themselves report that patient access to these services is uneven at best and that some of these changes are harming outcomes.

Many patients and their caregivers do not have the information they need to make informed decisions about treatment and recovery support services, leaving them at greater risk of the harmful consequences of addiction. The lack

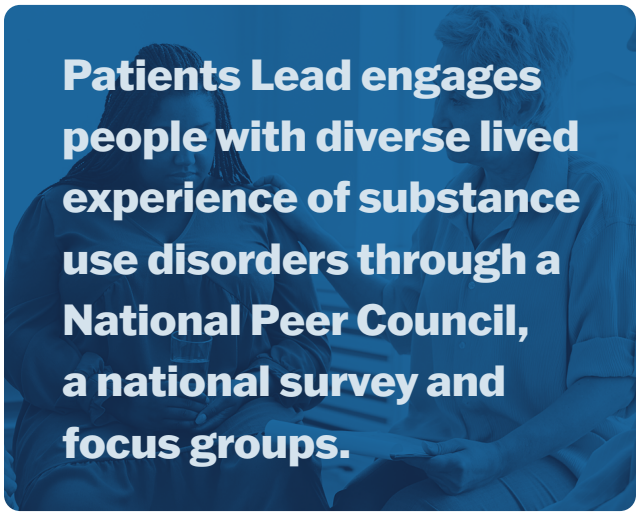
of information extends from what treatments work best to which specific providers have the best track records in achieving positive patient outcomes. Underlying these problems is another critical gap: what outcomes are important to patients?

Substance use disorders is a disease marked by frequent recurrences and a long-term trajectory to wellness, leading to a critical need for research on long-term outcomes. However, there is little information identifying which outcomes are most important to patients, with the exception of one study in Europe. Also, there is limited definitive research assessing and comparing which treatments best achieve the outcomes of most importance to patients.

This study is the first to identify treatment outcomes prioritized by people with substance use disorders across the nation. This is an essential step to refocusing research, treatment and public policy on those outcomes in order to more effectively address the national epidemic of substance use disorders. Centering these outcomes can result in more meaningful research results, more effective service providers, better outcomes for patients, and a healthier society.



III. Patients Lead Project



Community Catalyst, in partnership with Faces & Voices of Recovery and the American Society of Addiction Medicine (ASAM) is conducting the "Patients Lead" project, funded by the Patient-Centered Outcomes Research Institute (PCORI), to amplify the voices of people with lived experience of substance use disorders in shaping research and treatment to improve recovery outcomes. Patients Lead engages people with diverse lived experience of substance use disorders through a National Peer Council, a national survey and focus groups. Our initial goal is to help Patient-Centered Outcomes Research and Comparative Effectiveness Research (PCOR/CER) address outcomes most critical to patients, so research results better inform patients' choice of treatment. The ultimate goal of the project is to improve treatment outcomes by focusing research, policymaking and service delivery on what people with substance use disorders want and need.

As drug overdoses continued to rise during COVID-19 while treatment and services shifted, we enhanced our project with a COVID-19 focus and additional aims:

- Identifying the outcomes from treatment and recovery services that matter most to people with substance use disorders during this pandemic
- Engaging patients in developing research questions to help ensure COVID-19-related changes in the health system achieve those outcomes during future pandemics.

IV. Methods

This project bridges the research, clinical and recovery communities to improve treatment and services for people with substance use disorders. To achieve our project goals, our methods centered cross-sector engagement of the addiction research field (a project advisory committee of esteemed addiction researchers to guide project planning and design), members of the ASAM clinical community (two ASAM clinicians to advise the project team and engage with the National Peer Council directly), and the broader substance use disorders advocacy and recovery communities, including people with substance use disorders/people in recovery (the project National Peer Council, focus groups, and national online survey).

Engaging People with Lived Experience of Substance Use Challenges

People who have experience with substance use disorders treatment and services know what works and doesn't work for them. But too often, they are left out of policy decisions – like how treatment and recovery programs are designed, and the outcomes those programs seek to achieve. Therefore, engaging individuals with lived experience of substance use challenges to inform health system improvements is the heart of this project. Patients Lead followed a phased engagement plan, including broad outreach to advocacy networks to build awareness of PCOR, selecting a National Peer (Patient) Council to guide the project, and gathering input directly from community members though focus groups and a national online survey.

NATIONAL PEER COUNCIL

A primary Patients Lead project objective was to bring together a peer (patient) council, diverse in race, ethnicity, gender, age, socioeconomic status, geography and type of substance use disorder, to recommend the outcomes of treatment and services that matter most to people with substance use disorders, in order to guide research and action to improve treatment and services. Community Catalyst and Faces & Voices of Recovery promoted the council opportunity through email distribution lists and specific follow-up with state and local advocacy partners, with particular attention to recruiting applicants from historically oppressed and underserved communities, including Black, Indigenous and People of Color.

There was overwhelming interest in the National Peer Council opportunity with nearly 130 applicants—a testament to the eagerness of individuals to be involved in transforming the treatment, recovery and services systems. The project team finalized the 10-person council to be as representative of the United States population of people in recovery as possible. Members represent 10 states: California, Georgia, Massachusetts, Michigan, New Jersey, New Mexico, New York, Oklahoma, Utah, and Virginia. The group is diverse by race/ethnicity, age, gender, primary SUD substance, length of time in recovery, recovery pathway, and history of criminal legal system involvement. Council members were paid for their time.

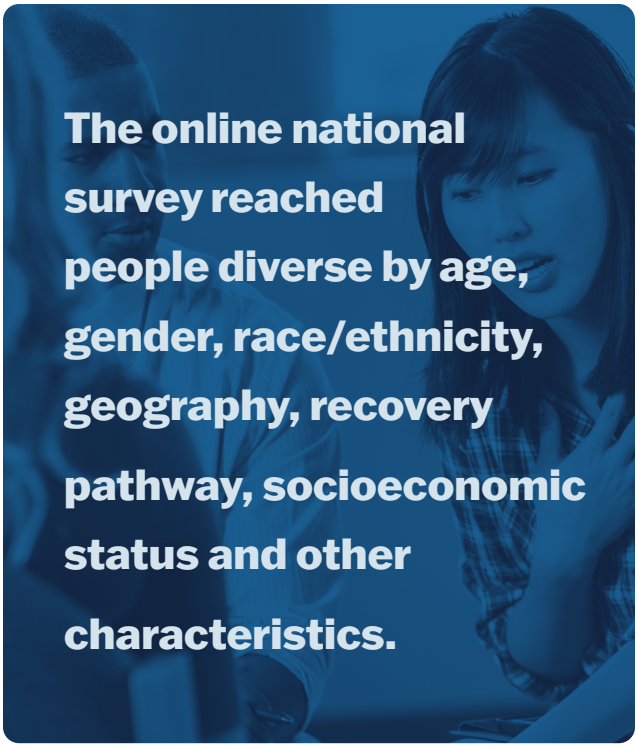
The National Peer Council is the grounding force to inform, guide and shape project activities. They met 10 times between June 2019 and March 2021. Council members were crucial in reviewing and contributing to survey design, and

to ensuring the questions were appropriate to our target audiences of people with substance use disorders and people in recovery. The council members also helped with survey dissemination and focus group recruitment to increase the diversity of responses. The council reviewed the data analysis and findings that project staff gathered from the national online survey and focus groups and made recommendations for this report.

NATIONAL ONLINE SURVEY

The project team, with input from the National Peer Council, research advisors and two prominent ASAM physicians, created a national survey to reach people across the United States to determine which treatment/recovery services outcomes are most important and whether those outcomes change during COVID-19. The survey was conducted online from September through early November 2020. People were eligible to complete the survey if they were at least 21 years old and had "lived experience with substance use challenges, including addiction." The project further defined eligibility as including people with substance use disorders, people who are using substances, and people in recovery (using their own definition of recovery). Those eligible also included family members of adults with substance use challenges, including those who have died from substance use.

The survey was disseminated through the networks of Community Catalyst, Faces & Voices of Recovery, and the American Society of Addiction Medicine across the country, via email lists, conference calls, webinars and direct outreach, yielding a convenience sample of 839 complete responses from 48 states. This total sample included people responding based on their own experience with substance use, their family member's experience with substance use, or both their own and family member's experiences. The project team recruited from every state across the country and reached people diverse



by age, gender, race/ethnicity, geography, recovery pathway, socioeconomic status and other characteristics, although the respondents were not fully reflective of the population with substance use disorders. (Selected demographic breakdown is included in the appendix.)

The survey asked individuals to select all outcomes they felt were important from a list of options, and then asked them to provide their top three most important outcomes in any order. Data regarding individuals' top three most important results were analyzed using descriptive statistics.

FOCUS GROUPS

To include in-depth community perspectives beyond the National Peer Council, the project team hosted virtual focus groups of people in recovery from across the country. The team recruited participants using the same methods as for the council, seeking a total of 50 people representative of the nation's diversity. The criteria mirrored that for the survey, but included targeted recruitment of people in states and from demographics underrepresented in the survey

and council. More than 500 people applied — further evidence that people with substance use disorders are enthusiastic about trying to improve services. The project team hosted nine virtual focus groups in English, engaging 53 participants in all. The focus groups were designed for participants to share the outcomes from substance use disorders treatment and recovery services most important to them and to explain why those were important. Participants were compensated for their time.

Research Advisors

PROJECT ADVISORY COMMITTEE

We invited esteemed addiction researchers and experts to guide project planning and implementation.

- Andrea Acevedo, PhD, Assistant Professor of Community Health, Tufts University
- Richard Frank, PhD, Professor of Health Economics, Harvard Medical School
- John F. Kelly, PhD, Director of the Massachusetts General Hospital Recovery Research Institute
- Walter Ling, MD, Founding Director of Integrated Substance Abuse Programs, UCLA
- Tami Mark, PhD, Senior Director of Behavioral Health Financing, RTI
- Carol McDaid, Principal at Capitol Decisions, Inc.

CLINICAL ADVISORS

Two ASAM members with a commitment to centering community voice in decision making advise the National Peer Council and the Patients Lead team: Dr. Chinazo Cunningham and Dr. Yngvild Olsen. They tapped their deep experience as clinicians treating individuals with substance use disorders to advise the council and project team in identifying the outcomes most important to patients, and analyzing how focusing on these outcomes can improve clinical care and outcomes. Advisors engage periodically with the council, review project materials, and help promote project results.

V. Results

Summary Results

The National Peer Council and project team identified the following outcomes as most important to people with substance use challenges, taking into account the voices of hundreds of people across the country expressed through the survey and focus groups and the council's own experiences.

1. **Staying alive**
2. **Improving quality of life**
3. **Reducing harmful substance use**
4. **Improving mental health**
5. **Meeting their basic needs**
6. **Increasing self-confidence/self-efficacy**
7. **Increasing connection to services and supports**

The detailed survey results and focus group findings used to develop the list of outcomes are described below.

National Online Survey Results

Individuals completed the survey based on: their own experiences with substance use challenges, their experience as a family member of someone with substance use challenges, or **both** their own experience, and experience as a family member. In total, the analysis for what individuals want for **themselves** is based on 721 responses, and the analysis for what individuals want for their **family members** is based on 445 responses. Please see Table 1.

TABLE 1

Survey responses based on:	#
My OWN experience with substance use	394
My OWN experience with substance use AND as a FAMILY MEMBER of someone who uses/used substances	327
Total included in "Self" analysis	**721**

Survey responses based on:	#
My experience as a FAMILY MEMBER of someone who uses/used substances	118
My OWN experience with substance use AND as a FAMILY MEMBER of someone who uses/used substances	327
Total included in "Family Member" analysis	**445**

This yields a full survey sample of 839 individuals. Please see Image 1.

IMAGE 1: **TOTAL SURVEY RESPONSES = 839**

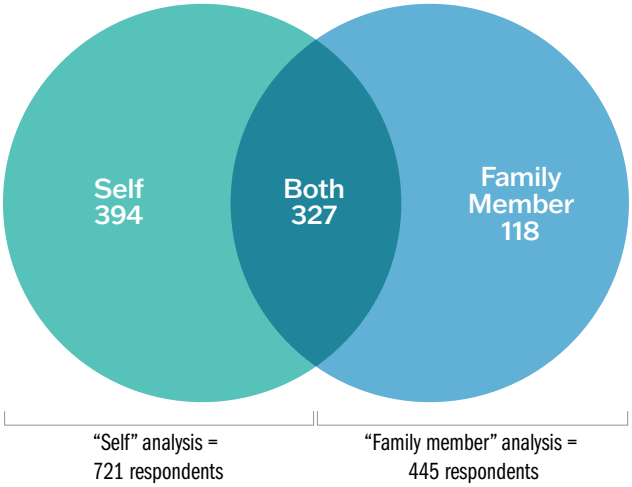


Table 2 shows the race/ethnicity and gender demographics of the 721 individuals responding for themselves.

TABLE 2: **RACE/ETHNICITY AND GENDER OF SURVEY RESPONDENTS SHARING THEIR OWN PRIORITY OUTCOMES**

Gender	# of respondents	% of respondents
Woman	408	57%
Man	236	33%
Transgender/Nonbinary	17	2%
Prefer not to answer/missing	60	8%
Total	**721**	**100%**
Race/ethnicity	**# of respondents**	**% of respondents**
White	513	71%
Black/African American	49	7%
Hispanic or Latino/Latina/Latinx	22	3%
American Indian/Alaska Native	11	2%
Asian	1	0.10%
Native Hawaiian/Pacific Islander	4	1%
Middle Eastern/North African	2	0.30%
Multiracial	46	6%
Prefer not to answer/missing	73	10%
Total	**721**	**100%**

(Additional demographic information available in the appendix.)

WHAT OUTCOMES DO INDIVIDUALS MOST WANT FROM TREATMENT AND SERVICES?

Survey respondents overall prioritized these top outcomes of treatment and services pre-COVID-19 for themselves (see Graph 1):

- Stay alive
- Have improved quality of life
- Stop all drug/alcohol use
- Improve mental health
- Address issues that come up in daily life

The prominence of "staying alive" as a top priority outcome may well reflect the life-threatening consequences of substance use disorders, and the barriers to treatment and recovery services. In society and in practice, abstinence is commonly regarded as the main goal of substance use treatment, but in our study, "stopping all drug/alcohol use" was not the top desired outcome overall or among any racial/ethnic demographic. Improving mental health featured prominently in the top desired outcomes, reinforcing the importance of assessing mental health needs even among people without an existing mental illness diagnosis.

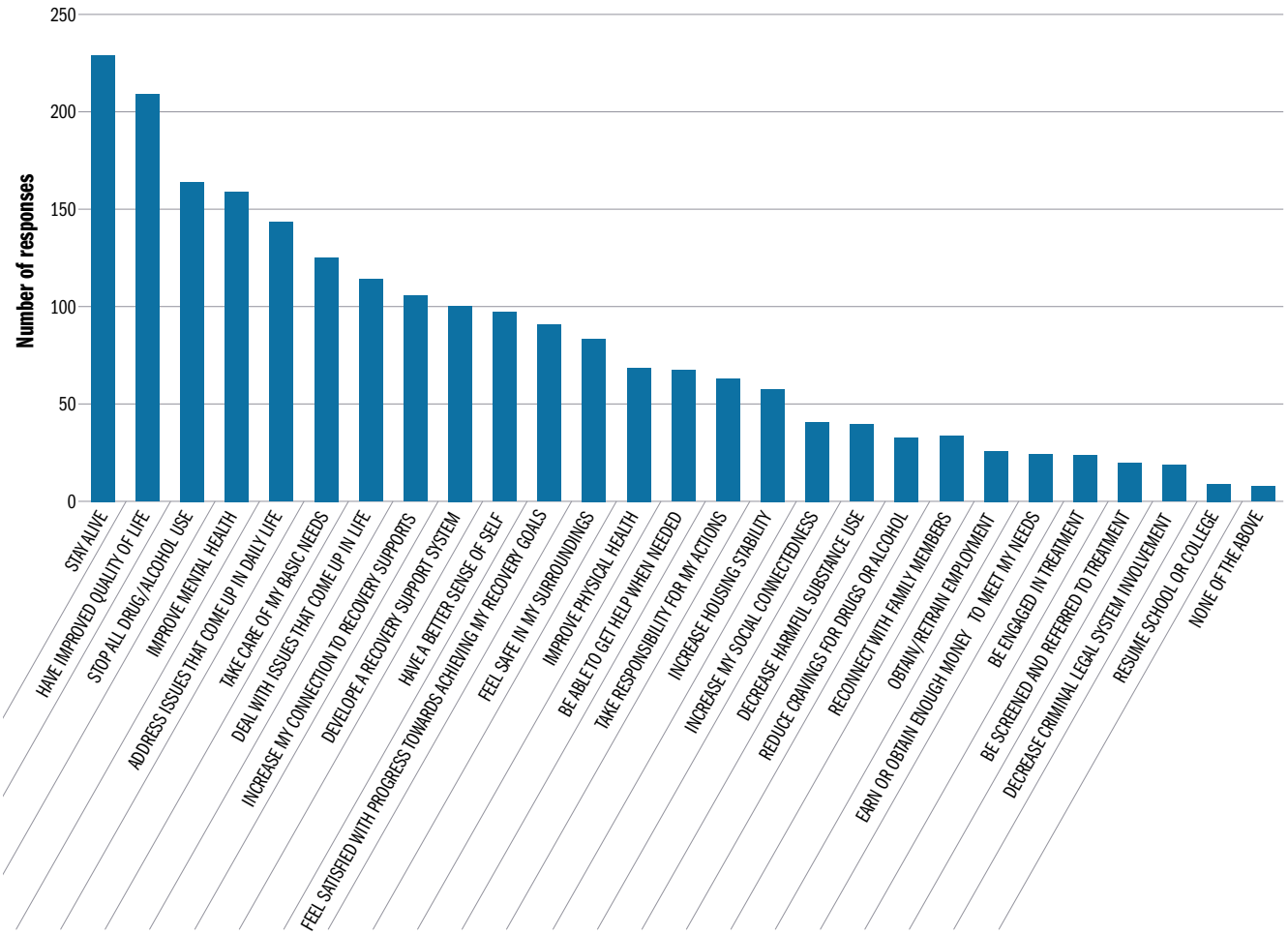
Responses by Race/Ethnicity

When examined by race/ethnicity, the top five outcomes overall appear in different priority order for some groups, and some are no longer in the top five (see Graph 2, page 14). The sample size is quite small for some demographics; further study is needed.

For example:

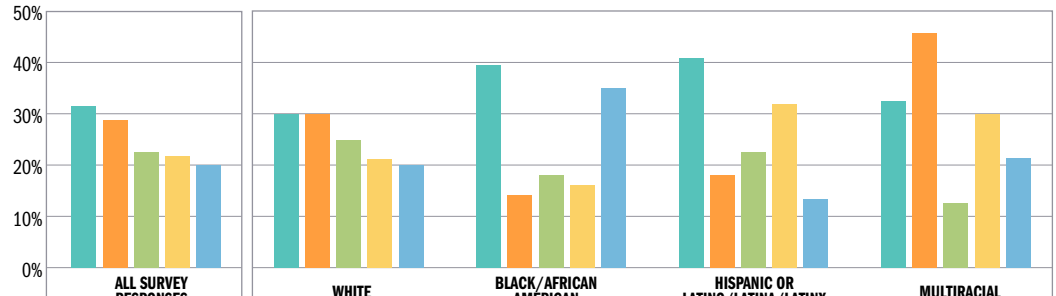
- 35 percent of Black/African American respondents said "address issues that come up in daily life" was most important, compared to 20 percent of white respondents and 14 percent of Hispanic/Latinx respondents.
- 25 percent of white respondents selected "stop all drug and alcohol use" compared to 13 percent of multiracial respondents. Notably, "stopping all drug/alcohol use" was not the highest desired outcome across any racial/ethnic demographic.
- 30 percent of white respondents prioritized quality of life, compared to 14 percent of Black/African American respondents.

GRAPH 1: **MOST IMPORTANT OUTCOMES: RANKED HIGHEST TO LOWEST BASED ON NUMBER OF RESPONSES**



TOP RESULT FROM TREATMENT OR SERVICES - *RESPONDENTS SELECTED UP TO 3*

GRAPH 2: **HOW DO THE TOP OVERALL SURVEY RESULTS DIFFER BY RACE/ETHNICITY OF THE RESPONDENT?**



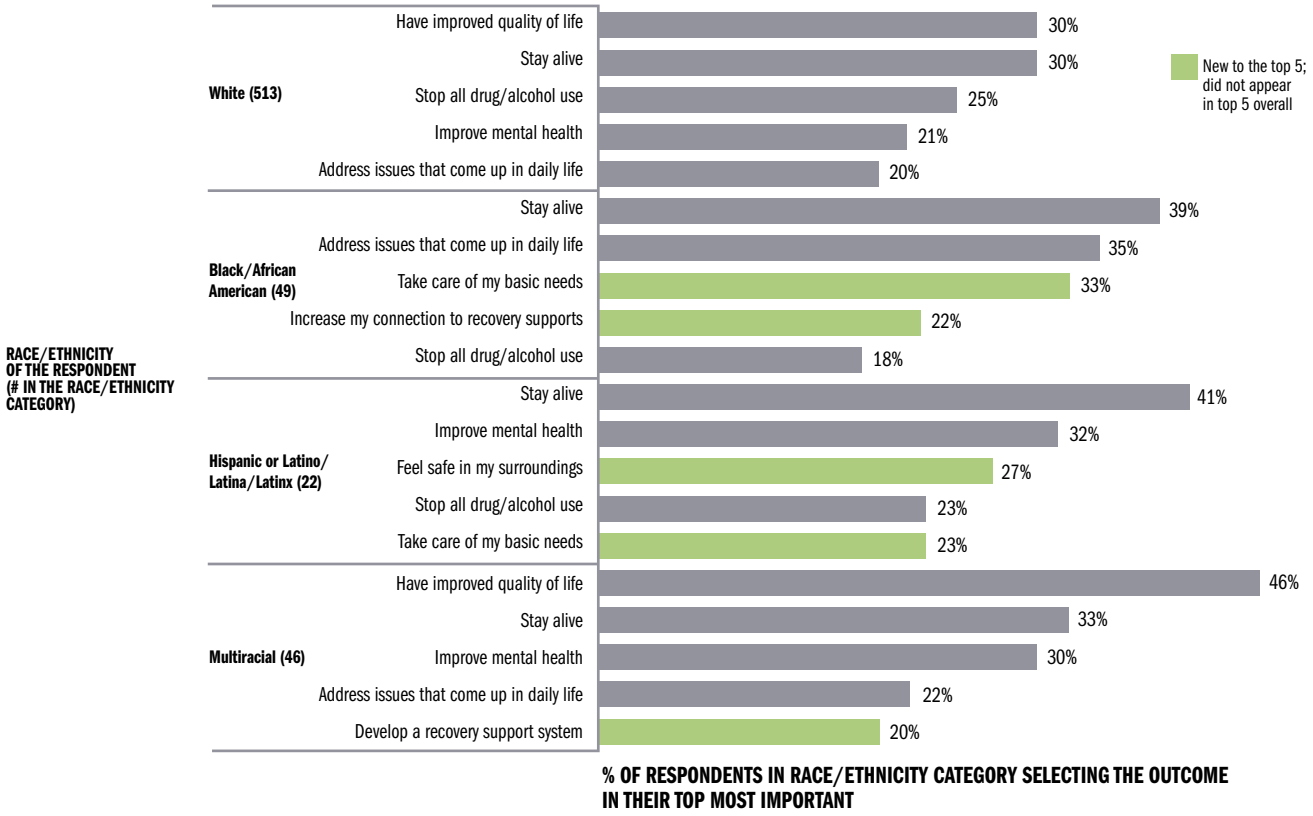
	ALL SURVEY RESPONSES	WHITE	BLACK/AFRICAN AMERICAN	HISPANIC OR LATINO/LATINA/LATINX	MULTIRACIAL
Stay alive	32%	30%	39%	41%	33%
Have improved quality of life	29%	30%	14%	18%	46%
Stop all drug/alcohol use	23%	25%	18%	23%	13%
Improve mental health	22%	21%	16%	32%	30%
Address issues that come up in daily life	20%	20%	35%	14%	22%
(# in the race/ethnicity category)	(721)	(513)	(49)	(22)	(46)

Data not shown due to small sample size for: American Indian/Alaska Native; Asian; Native Hawaiian/Pacific Islander; Middle Eastern/North African respondents

In addition, there were several outcomes that rose to the top five in the analysis by race/ethnicity that are not reflected in the top five responses from the overall sample (see green bars in Graph 3). These are:

- "Take care of my basic needs" (eating, showering/bathing, doing laundry, etc.): 3rd highest among Black/African American respondents; tied for 4th highest among Hispanic/Latinx respondents
- "Feel safe in my surroundings": 3rd highest among Hispanic/Latinx respondents
- "Develop a recovery support system": 5th highest among multiracial respondents.

GRAPH 3: **WHAT ARE THE MOST IMPORTANT OUTCOMES ACROSS DIFFERENT RACES/ETHNICITIES?**

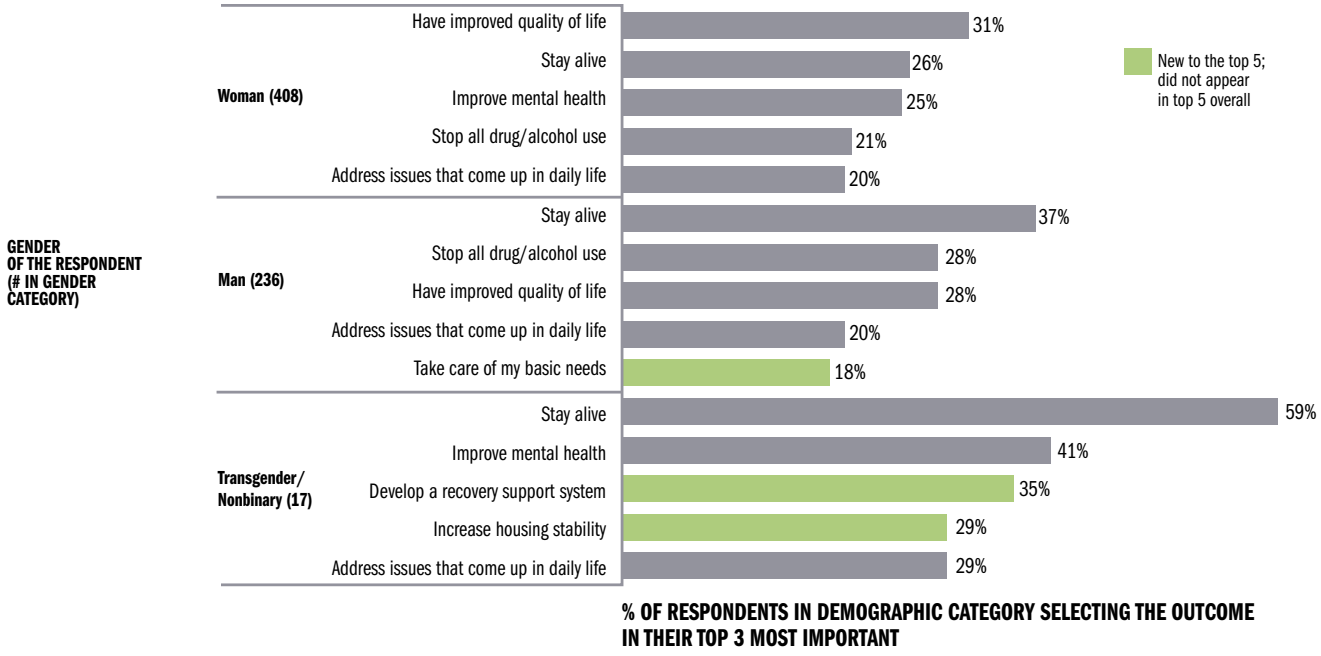


Responses by Gender

The top five outcomes overall appear in different priority order by gender, and there are some new outcomes rising to the top (see green bars in Graph 4):

- Among men responding, 18 percent selected "take care of my basic needs" (eating, showering/bathing, doing laundry, etc.)
- Among transgender/nonbinary respondents, 35 percent selected "develop a recovery support system" and 29 percent selected "increase housing stability." Note: The sample size (17) is quite small for transgender/nonbinary; further study is needed.

GRAPH 4: **WHAT ARE THE MOST IMPORTANT OUTCOMES ACROSS DIFFERENT GENDERS?**



Responses by Socioeconomic Status

Survey findings did not show an overall difference comparing responses by socioeconomic status. Comparisons by socioeconomic status were based on comparing the top responses for individuals who agreed with any of the following statements to responses from those who did not:

- Worried about whether their food would run out before they got money to buy more
- Worried about losing housing or being homeless
- Worried about finding, or losing, a job
- The electric, gas, water, oil, or internet company threatened to shut off services where they live

Given results of the survey showing differences across race and gender, it is surprising that differences did not appear across socioeconomic status. Given the limitations of this study, more outcomes research across socioeconomic status is needed. Please refer to the study limitations for more detail.

Outcomes Prioritized During COVID-19

We asked survey respondents whether *different results become more important during a pandemic like COVID-19.* Eighty percent of respondents said that the top results they want from treatment and services do **not** change during a pandemic like COVID-19.

The 20 percent of people who chose *different results during COVID-19* prioritized:

- Feel safe in surroundings
- Stay alive
- Improve mental health
- Increase connection to recovery supports
- Take care of basic needs

Safety, connection to recovery supports, and taking care of basic needs become more important, replacing "improved quality of life," "stop all drug/alcohol use," and "address issues that come up in daily life" among the top five outcomes. As COVID-19 wreaked havoc across the nation, threatening individuals' day-to-day activities, it is not surprising that improving

mental health remained a priority, and the ability to feel safe, increase connection to recovery supports, and care for basic needs became more important than stopping all drug/alcohol use and improving quality of life.

Combining all responses regarding outcomes during the pandemic —carrying over the top results for people who want the same things during COVID-19 as pre-COVID-19 and adding the new responses for those who want something different during COVID-19—the top five most important results people want for themselves during COVID-19 are:

- Stay alive
- Have improved quality of life
- Improve mental health (replacing "stop all drug/alcohol use" which was #3 pre-COVID)
- Stop all drug/alcohol use
- Address issues that come up in daily life

While the ranked order is slightly different, the overall top outcomes are the same before COVID-19 and during COVID-19.

In their own words: Why different results become more important during a pandemic:

> "Mental health issues are on the rise with COVID-19, so even more critical to address. Also, more critical to have safe, secure housing during times of needing to quarantine, etc."

> "Isolation and withdrawing are deadly for those with substance use disorder. With proper mental hygiene and a support network someone is more likely to deal with big issues without using just to cope. They have developed better coping skills."

> "Because the basics are harder to achieve during the pandemic. Just keeping people alive and safe is the greatest challenge and the first step in offering a path to recovery."

For the few individuals in our survey (23 people) who tested positive for COVID-19 or had COVID-19 symptoms, the top four highest outcomes pre-COVID-19 and during COVID-19 were:

- Have improved quality of life
- Stay alive
- Take care of my basic needs
- Stop all drug/alcohol use

The 5th highest outcome pre-COVID-19 was "improve mental health" while the 5th highest outcomes during COVID-19 were (tied) "feel safe in my surroundings" and "develop a recovery support system." This is in line with the overall finding that safety becomes especially important during a pandemic like COVID-19.

What Outcomes Do Individuals Want for Their Family Members?

We asked survey respondents to identify priority outcomes for family members with substance use challenges. The 445 respondents included some people who have substance use challenges themselves, and some who do not.

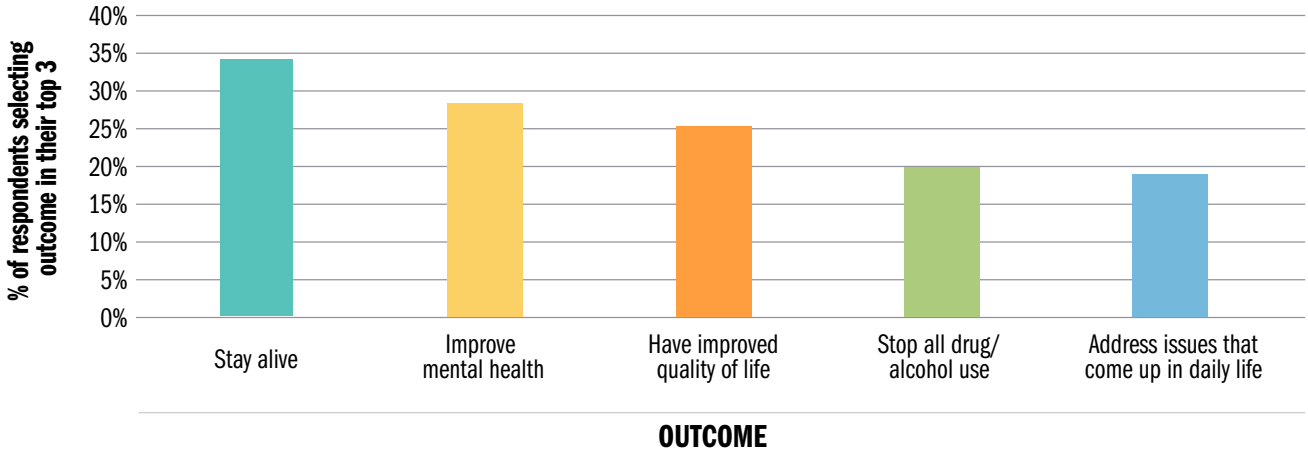
Overall, the top five outcomes that 445 respondents want for their family members are the same as those that 721 respondents want for themselves, in a slightly different ranked order:

- Stay alive *(same as top overall for self)*
- Improve mental health *(2nd highest overall for self was improved quality of life)*
- Have improved quality of life *(3rd highest overall for self was stop all drug/ alcohol use)*
- Stop all drug/alcohol use *(4th highest overall for self was improved mental health)*
- Address issues that come up in daily life *(same as overall for self)*

(See Graph 5 below and Graph 1 for comparison)

We did not ask respondents to provide demographics for their family member. Given the differences in survey responses across demographics in identifying outcomes for themselves, it's likely there are also differences across demographics in the outcomes people want for their family members. We suggest future research explore this as part of continued efforts to identify patients' desired outcomes and to provide culturally effective services.

GRAPH 5: **TOP OVERALL OUTCOMES THAT INDIVIDUALS WANT FOR THEIR FAMILY MEMBERS (N=445)**



Focus Groups Findings

Nine focus groups were co-facilitated by project team members from Community Catalyst and Faces & Voices of Recovery. Groups ranged in size from four to eight participants with a total of 53 participants. The participants ranged from 21 to 75 years old and came from 30 states. We engaged 32 women, 17 men, 2 nonbinary people, 1 transgender man, and 1 androgynous person. The racial and ethnic breakdown of participants was: 35 whites, 9 Black/African American, 7 American Indians/Alaska Natives, 3 Hispanics/Latinx, and 2 Asians. Further demographic details are in the appendix. Focus group facilitators followed a similar script for each group discussion, using three primary prompts:

1. Complete this open-ended question: "As a result of treatment or services for problematic use of alcohol or drugs, I think a person should be able to:____."
2. Of all the things that were just shared, which are most important to you? Why?
3. What changes in treatment or services need to be made in order to get these important results?

The project team adapted focus group discussions during COVID-19 and asked whether desired results changed during COVID-19, and if virtual services have helped individuals achieve what's important to them. Instead of selecting outcomes from a pre-populated list, focus group participants answered open-ended questions and could share whatever came to mind. Focus group participants identified different desired outcomes from survey respondents, perhaps in part due to the discussion format and the influence of **social desirability.** The most common outcomes of treatment and recovery services that focus group participants prioritized are:Increase their connection to community and recovery services

- Increase their self-confidence and empowerment
- Connect to a supportive network of community members
- Meet their basic needs and increase life skills
- Reduce substance use and harmful behaviors, including through harm reduction

During COVID-19, participants reiterated the importance of treatment and services resulting in connection to a support network, and to a full range of services, especially emergency and dual diagnosis services. Connection to virtual services was also an important outcome during COVID-19 among focus group participants. When in-person services are not possible and virtual services become the only option, participants said the ability to access technology and instruction on virtual services is an essential treatment outcome to ensure continuity of care.

In their own words:

> "Self-confidence... If you have that confidence, you are more prone to being proactive in your recovery."

> "Most important outcome for me is how I can maintain those connections. Someone mentioned networks, support systems. All those things are ways to remain connected. I see the opposite of addiction is connection."

Focus group participants said treatment and services should be changed in the following ways to better achieve these results:

- **Increase the availability of services, especially peer support services and other community services provided by Recovery Community Organizations:** Participants suggested increasing treatment options that are not linked to the criminal justice system, and providing more options for people to find treatment willingly.
- **Make treatment and services easier to access:** Participants recommended making treatment and services more affordable and removing barriers to insurance.
- **Bridging treatment gaps:** Participants recommended expanded care coordination so people can easily access continuous treatment and services when they need it and they do not fall through the cracks.
- **Use individualized treatment approaches:** Participants said treatment needs to "meet people where they're at" and follow harm reduction approaches.
- **Provide trauma-informed and culturally effective services:** Participants noted that trauma is at the root of many people's substance use. They also said some providers need greater awareness of their implicit biases and privileges in order to provide care that achieves better outcomes.

National Peer Council Discussions

Over many months, the council reviewed the survey results and focus group findings and drew on their own experiences to identify categories of outcomes as most important. Please refer to the *Discussion* section for their conclusions and explanation.

VI. Discussion

This first national examination of the treatment outcomes prioritized by people with substance use challenges clearly identifies the need to reshape research, clinical services and policies to address the national epidemic of substance use disorders. The priority outcomes reflect the broad expectations people have for treatment ensuring their survival and improving their lives, and the lesser priority they place on completely stopping all drug and alcohol use. The results also highlight the range of priority outcomes across different demographics and drive home the need for treatment that is both tailored to individual desired outcomes, and culturally and linguistically effective.

The changes occurring in our society during this research make acting on these findings more urgent. COVID-19 swept the nation, taking lives and making people fearful for their survival, disrupting employment and increasing the social isolation that feeds substance use. Drug overdoses are increasing, and demand for addiction services is growing. Amid a period of national reckoning on racial injustice, COVID-19 has laid bare the inequities of the health system, as those who already face unequal and discriminatory treatment continue to be hit hardest. Meanwhile, addiction continues to be criminalized, especially among Black and brown communities.

As policymakers, health care providers and researchers work toward a more just and effective health system, they must include a focus on substance use disorders. These project findings show the importance of providers understanding individuals' treatment and recovery goals, and fostering pathways to health with culturally effective services tailored to the person's desired outcomes and intersecting identities.

The Patients Lead National Peer Council and project staff and experts from Community Catalyst, the American Society of Addiction Medicine, and Faces & Voices of Recovery assessed the data gathered through focus groups and survey findings from people of different backgrounds all over the country. They identified these outcomes of substance use treatment and services as the most important to individuals with lived experience:

1. STAYING ALIVE

Staying alive received the highest number of responses in the survey—32 percent of all survey respondents selected this as one of their top three most important outcomes from treatment and services. Disaggregated data showed this was also a top outcome among white, Black/African American and Hispanic/Latinx respondents. Family members of people with substance use challenges also prioritized "staying alive" for their loved ones. The project team notes that there could be many reasons why survival is top of mind for respondents, particularly in the context of a global pandemic, and related to other intersecting factors such as race- and gender-based discrimination. In addition, social shame, stigma within the health system, and punitive responses from the criminal legal system combine to make it especially hard for individuals with substance use challenges to access care that is right for them.

This finding suggests the need for more extensive harm reduction approaches, such as overdose prevention and syringe services, and incorporation of these strategies more fully into the continuum of care offered all

patients. It also calls attention to the value of addressing immediate and life-threatening health concerns in addition to substance use. Closely related conceptually to this outcome is the need to ensure individuals' ability to feel safe in their surroundings, an outcome prioritized by 12 percent of survey respondents.

2. IMPROVING QUALITY OF LIFE

Improved quality of life was a top survey outcome overall, and within the top five for white and multiracial respondents. Focus group participants also placed importance on achieving better quality of life. This suggests researchers should intensify their recent efforts to measure quality of life outcomes from substance use treatments. It also underscores that a more holistic approach to substance use treatment, including other health care and social services, would more likely achieve patients' desired outcomes. This person-centered approach would focus on multiple facets of a person's life.

3. REDUCING HARMFUL SUBSTANCE USE

Reducing harmful substance use was a top desired outcome from focus groups and the National Peer Council. Twenty-three percent of survey respondents went further, prioritizing "stop all drug/alcohol use" in their top five most important outcomes. However, this abstinence-based outcome did not come up as a priority during focus groups, nor was it the top response across any demographic in the survey. This finding suggests that researchers and clinicians need to reduce the emphasis on abstinence as an outcome, and shift to viewing substance use on a continuum. Pathways to successful outcomes may be sobriety/abstinence for some, while for others the pathways may be reduced use or harm reduction, including switching from a more deadly substance to a less harmful one. This is especially important for future PCOR, as many researchers focus on abstinence-based outcomes.

4. IMPROVING MENTAL HEALTH

Improving mental health appeared within the top five outcomes among white; Hispanic/Latinx; and multiracial respondents. Focus group participants also highlighted the importance of dual-diagnosis services (substance use disorders and mental illness), especially during COVID-19. The pandemic has caused increases in mental health concerns across the country. Given the frequent co-occurrence of substance use and mental illness, this finding suggests treatment for substance use disorders must not be siloed from mental health treatment. Clinicians should assess patients' mental health needs and be prepared to incorporate a focus on improving mental health.

5. MEETING THEIR BASIC NEEDS

Focus group participants across multiple groups cited as a top outcome the ability to ***meet their basic needs,*** such as food, clothing, and housing. Taking care of basic needs—described in the survey as eating, showering/bathing, doing laundry, etc.–– was among the top five desired outcomes for Black/African American and Hispanic/Latinx survey respondents. Housing stability was a top outcome among trans/nonbinary respondents. Addressing issues that come up in daily life—described in the survey as getting through the day, handling responsibilities, etc.— was also a top outcome across many races, and 4th highest for transgender/nonbinary respondents. The National Peer

Council also emphasized the significance of fulfilling immediate needs of survival, such as food and housing. They also placed importance on addressing daily challenges as a means of taking accountability and feeling empowered in a recovery pathway. Although most in the health field are aware of the role of social determinants in patient health, these basic needs and the ability to carry out activities of daily life are not often a top priority in PCOR or clinical care. This needs to change to improve treatment outcomes.

6. INCREASING SELF-CONFIDENCE/ SELF-EFFICACY

Increasing self-confidence was a top outcome across multiple focus groups. This category includes other similar outcomes focus group participants highlighted such as increased self-love, increased self-sufficiency, ability to cope with struggles, autonomy, and increased self-advocacy/self-empowerment. They focused on reduction of self-shame and stigma, and the ability to live up to their own potential. They also placed importance on being better able to manage their life and situations and being able to determine their individual recovery pathways. These themes of improved self-efficacy also came through strongly during National Peer Council discussions. Although health confidence is an area of research in clinical care, it is not often looked at through the lens of substance use treatment other than perhaps through the strong and pervasive impact of stigma. The importance of this outcome suggests the need for more research using this area of outcomes, as well as more interventions and trainings to increase patients' self-confidence in both clinical and recovery services settings.

7. INCREASING CONNECTION TO SERVICES AND SUPPORTS

Increasing connection to services and supports was a top focus group outcome and included connection to community, and connection to recovery services, including long-term services. For example, many cited the ability to get help when needed and connect to services after leaving treatment as an essential outcome. Participants also emphasized the need to be able to connect to a support network, and the ability to access resources to meet their individual needs. This is closely related to the outcome "develop a recovery support system," a top outcome for transgender and nonbinary respondents in the survey findings. The importance of ongoing connection to recovery supports is increasingly recognized, but facilitating this connection is not consistently practiced or paid for. The priority patients place on this outcome suggests the need to strengthen the relationship between clinical treatment and recovery support services in the community.

Focus group participants and National Peer Council members said connection to community and virtual services was a particularly important outcome during COVID-19. With social distancing required and in-person services harder to access, the ability to access technology and instruction on virtual services became an essential treatment outcome.

Gaps in Current Research

Current research doesn't comprehensively address these outcomes. Several of the top outcomes selected by survey respondents are not commonly the focus of outcomes research or clinical practice to improve substance use services.

In most clinical research, treatments are evaluated on reduction in use or abstinence from alcohol or drugs. Other outcomes occasionally studied include reductions in illegal activities, increases in employment, and "staying alive", which is more commonly measured as mortality.

Other studies have used broader outcomes, such as quality of life (also studied as health-related quality of life or overall quality of life). As one study notes, the variety of tools to measure quality of life as well as the various types of substance use disorders have left many unanswered questions in this area. Clearly, there is a need for more research on how and which substance use disorders services improve quality of life.

Improving mental health, meeting basic needs, increasing self-confidence / self-efficacy, and increasing connection to services and supports are all under-studied areas as outcomes of substance use disorders care. Substance use and mental health have been studied as comorbidities; however, mental health is not typically used as an outcome to indicate success of substance use treatment. Similarly, basic needs such as housing are studied in relation to substance use disorders, but meeting these needs is typically not an examined outcome. In the area of self-confidence / self-efficacy, a few studies have looked at facets such as the health literacy of patients or the impact of self-monitoring, but the research is not extensive. Lastly, connection to services and supports is rarely used as an outcome. One study looked at women's recovery networks, but used sobriety as an outcome to evaluate results. Additional research in these areas is essential to help improve patient outcomes.

Other Changes Needed

Another step forward would be incorporating the outcomes identified in this project into ongoing initiatives. Efforts such as Shatterproof's ATLAS, designed to help consumers find care that meets their needs, can incorporate these outcomes to better inform patients. Groups focused on quality measurement, such as the National Quality Forum, could consider these outcomes in fostering development of measures. Insurers could then incentivize the use of these measures, and track whether service providers are achieving these outcomes.

As suggested by studies on long-term recovery, treatment satisfaction, and continued care, the common current practice of evaluating substance use services by collecting data on the number of people receiving services is flawed. It does not yield information on the quality of care nor how effective it is.

Some individuals with substance use disorder do receive treatment that helps them achieve their desired outcomes, and 76% of survey respondents in this study said some treatment or services they received helped them achieve their top three results. However, most offered extensive comments on the need for improved services. In order to transform addiction services and meet people's need and goals, outcomes identified by people with lived experience in substance use must be the focus.

Additional Context for Interpreting the List of Seven Outcomes

It is important to take account of differences in desired outcomes across demographics including race/ethnicity and gender, while also acknowledging that specific recovery goals will vary from person to person. We have highlighted these differences not to presume that every person in these demographic categories will always prioritize these same outcomes, but to emphasize the importance of providing individually tailored services that meet the needs of people as individuals, taking into account their race/ethnicity, gender, and other intersecting identities.

The National Peer Council noted that the voices of highest need populations were likely not included in this project, as the focus groups and survey were conducted online and relied on participants having internet access and a computer/mobile device. Council members doing direct street outreach and providing services among highest need areas and homeless communities emphasized that basic needs such as taking a shower might be immediate desired outcome for those individuals. For them, quality of life might be farther down the line. This lifts up the importance of additional research with these populations, as well as efforts to see how desired outcomes change over the course of engagement in services.

Please refer to the appendix for project limitations. More research is needed to build on these project findings, particularly focused on populations underrepresented in this project, such as Black, Indigenous and People of Color and transgender/nonbinary people, as well as populations the project team did not engage at all, such as incarcerated individuals and people with disabilities.

VII. Recommendations

The following recommendations (pages 27-32) are tailored to policymakers, service providers, and researchers. The recommendations stem from the national survey results, focus group findings, National Peer Council meetings, and discussions with the project team and advisors. The goal of these recommendations is to promote addiction policies, services, and research centered on the outcomes that matters to individuals — including those identified above:

1. Staying alive
2. Improving quality of life
3. Reducing harmful substance abuse
4. Improving mental health
5. Meeting their basic needs
6. Increasing self-confidence/self-efficacy
7. Increasing connection to services and supports

These recommendations provide the foundation for progress to ensure substance use disorders treatment and services are designed and delivered in a way that helps individuals seeking those services achieve the outcomes they want.

RECOMMENDATIONS FOR POLICYMAKERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Increase funding for the full continuum of services, from prevention and early intervention, including harm reduction and crisis services, to inpatient and outpatient treatment, to residential services and long-term peer recovery supports, including those provided by recovery community organizations.		X					X
Increase funding for community-based services for people with substance use disorders, including nutrition assistance, low-barrier housing, and other services that meet individuals' basic needs. Dedicate funding to make these services interconnected and easy to navigate, including reentry services for people returning to the community from incarceration.	X				X		X
Target funding for harm reduction programs that focus on keeping individuals alive and reducing harm during their recovery, for example overdose prevention and syringe services; also, fund provider education on harm reduction.	X		X				
Expand access to all forms of medication assisted treatment (MAT); make permanent the temporary policies enabling telephonic prescribing and counseling and continue the flexibility of take-home doses for medicines.	X	X	X				X
Mandate that insurance cover the services needed to help achieve outcomes prioritized by patients.	X	X	X	X	X	X	X
Put in place mechanisms to hold providers accountable for achieving outcomes prioritized by patients, including helping individuals with substance use disorders to stay alive.	X						
Ensure essential services are affordable by supporting Medicaid and private insurance subsidies, as well as safety net providers for those without insurance.	X	X					X

RECOMMENDATIONS FOR SERVICE PROVIDERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Clarify each individual's desired treatment and recovery goals and adjust services to meet those goals. Tailor services to each individual's desired short-term and long-term outcomes and needs, providing a culturally effective whole person approach, multiple pathways including self-directed, a full continuum of health and social supports, and addressing co-occurring conditions and trauma. Provide services 24 hours a day, 7 days a week.	X	X	X	X	X	X	X
Provide 24/7 crisis support, harm reduction services including infectious disease testing, and safe locations to await treatment if services aren't available on demand.	X		X		X		X
Focus on promotion and on-the-ground outreach to community members to ensure people needing treatment, services, and recovery supports are aware of how and where to find them. Hire peers to conduct this outreach.							X
Expand access to all forms of medications for addiction treatment, and tailor treatment duration based on the individual's needs, including developing therapeutic processes for tapering medication if requested. Assess differences in access and outcomes of participants/patients by race, gender, and other demographics. Provide culturally and linguistically effective care to reduce inequities in access and outcomes.		X	X				
Integrate mental health supports into substance use disorders services even for individuals without a documented mental illness diagnosis.				X			X
Help individuals find ways to reduce isolation, particularly by increasing connection to services and to the recovery community. This is especially important for those early in their recovery who may not yet have an established recovery network.	X						X

RECOMMENDATIONS FOR RESEARCHERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Investigate which treatments, recovery pathways (including nontraditional pathways), and recovery support services are most effective in helping individuals achieve their priority outcomes.	X	X	X	X	X	X	X
Help expand the medications available to treat substance use disorders by studying new medications and new uses of existing medications, looking at short- and long-term safety and effectiveness.	X	X	X				
Compare various tools that assess aspects of quality of life including WHO's measurement tool and the Recovery Capital Scale.		X					
Stratify all comparative effective research (CER) and patient-centered outcomes research (PCOR) related to substance use disorders by race/ethnicity and gender, and report findings by these demographics to inform culturally effective clinical recommendations and policy solutions.		X				X	
Expand community-based research efforts by partnering with grassroots organizations to assess desired and achieved outcomes of specific populations, especially among Black, Indigenous and People of Color, LGBTQ+, and other marginalized groups.						X	X
Conduct further research identifying the outcomes individuals prioritize from treatment/services for substance use disorders. In particular, explore the outcomes that matter most to people with marginalized identities to understand why differences exist and to inform policy decisions that make services more equitable.	X	X	X	X	X	X	X

SPECIFIC TO VIRTUAL SERVICES OR TELEHEALTH, DURING COVID-19 AND BEYOND

These recommendations stem from National Peer Council discussions and two focus groups hosted during COVID-19 that directly examined access to virtual services and effectiveness of those services in achieving patients desired outcomes.

VIRTUAL RECOMMENDATIONS FOR POLICYMAKERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Fund the expansion of broadband and Wi-Fi, as well as purchase or loan of cell phones and tablets for use in virtual services.		X			X		X
Fund payment for continuation of virtual services beyond the COVID-19 public health emergency period.	X						X
Create and fund a designated team or group of volunteers focused on disaster response in the substance use recovery community modeled after the Federal Emergency Management Agency (FEMA). They named this Recovery Emergency Management Agency (REMA). The team could include peer workers, nurses, and technology personnel, specifically focused on providing support and services to people in recovery and people who are homeless, as well as testing for contagious diseases. Focus group participants suggested establishing a virtual video-enhanced 24-hour online crisis hotline and "satellite" offices.	X				X		X
Provide community-based hubs where people can safely learn how to use virtual services/platforms, get assistance using them and where those who do not have devices phones/computers) can safely access these privately for appointments and groups.		X				X	X

VIRTUAL RECOMMENDATIONS FOR SERVICE PROVIDERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Continue to provide expanded virtual services even when it is safe to return to in-person services, but maintain both as patient-chosen options.		X					X
Provide a directory of virtual services, including what services are available and how they can be accessed. Focus on consistency in virtual service access, timing, management, quality, and availability so virtual services are reliable and participants are confident about how to access them. Concentrate on promotion and on-the-ground outreach to community members.						X	X
Incorporate advanced training for providers on active listening skills, such as non-verbal cues, and motivational interviewing techniques as this can be more difficult in virtual settings; provide training for patients on how they can use technology to access virtual platforms.				X		X	X

VIRTUAL RECOMMENDATIONS FOR RESEARCHERS	OUTCOMES						
	STAYING ALIVE	IMPROVING QUALITY OF LIFE	REDUCING HARMFUL SUBSTANCE USE	IMPROVING MENTAL HEALTH	MEETING BASIC NEEDS	INCREASING SELF-CONFIDENCE/SELF-EFFICACY	INCREASING CONNECTIONS TO SERVICES AND SUPPORTS
Explore who has not been able to access virtual services, particularly focusing on rural, low-income, and homeless populations, and identify solutions to increase access among these and other under-resourced communities.					X		X
Study which types of virtual technology work best to enhance access to services, including what types achieve the best patient engagement, and what supports/training people need to use them.							X
Determine what workforce capacity is need for the most effective virtual services.							X
Compare outcomes from virtual services to those from in-person services, using the outcomes most important to patients. Study this question separately for peer support services and for other categories of services.	X	X	X	X	X	X	X
Investigate how clinicians and peer services providers can best ensure the safety and privacy of patients during virtual care, exploring both physical and emotional safety.				X		X	X
Research the best ways to ensure provider accountability in virtual services.	X	X	X	X	X	X	X

The National Peer Council also recognizes that society must make major changes to ensure that everyone gets the health care they need to achieve positive outcomes from treatment of substance use disorders. They identified a few of these changes: treating addiction as a public health issue instead of a criminal one; working to end stigma and prejudice against people who use drugs; addressing structural racism and other discriminatory policies; and enforcing anti-discrimination and anti-predatory policies in treatment facilities, especially regarding transgender and nonbinary people. The targeted recommendations above provide essential steps forward.

VIII. Conclusion

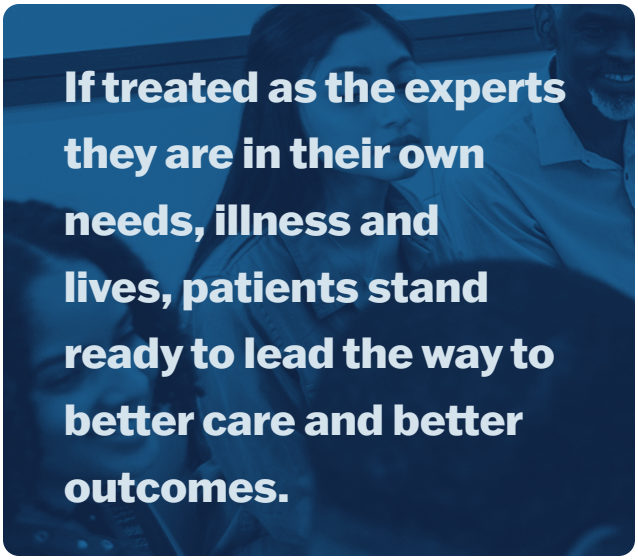
As addiction continues to plague our nation, this groundbreaking study of the outcomes people with substance use disorders want from treatment and recovery services lays the foundation for patient-centered solutions. Patients Lead participants identified these priority outcomes:

1. Staying alive
2. Improving quality of life
3. Reducing harmful substance abuse
4. Improving mental health
5. Meeting their basic needs
6. Increasing self-confidence/self-efficacy
7. Increasing connection to services and supports

Several of these outcomes are not commonly the focus of research or clinical standards to improve the quality and effectiveness of substance use services.

Achieving these outcomes requires rethinking and reshaping research and services, and changing policies that govern funding, quality and access to those services. The recommendations above provide a starting point.

This investment in system improvement is particularly important during COVID-19, when in-person services are hard to access, feelings of isolation are common and drug overdoses are increasing. The investment is an essential part of our nation's reckoning with racism in our criminal legal system and health system, since addiction continues to be criminalized, especially among Black and brown communities.



The Patients Lead research identified priority outcomes, but also found important differences across race and gender. Additional research focusing on Black, Indigenous and People of Color and transgender and non-binary people is needed to confirm and understand those differences. However, it is clear that effective substance use disorders treatment and recovery support services must be tailored to individuals' desired outcomes and needs and must be culturally and linguistically effective.

This project has engaged more than 875 individuals from across the country with lived experience of substance use disorders, and hundreds more wanted to participate in focus groups and join the National Peer Council—a testament to their eagerness to be involved in transforming treatment and recovery support services. This level of engagement confirms that, if treated as the experts they are in their own needs, illness and lives, patients stand ready to lead the way to better care and better outcomes. Following their lead will undoubtedly save lives.

IX. Appendix

A. ACKNOWLEDGEMENTS

NATIONAL PEER COUNCIL ADVISORS, AMERICAN SOCIETY OF ADDICTION MEDICINE

- Dr. Chinazo Cunningham, Professor of Medicine, Montefiore Health System and Albert Einstein College of Medicine
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Lastly, the team extends our gratitude to the hundreds of individuals across the country with lived experience of substance use, who made time to engage with this project through the online national survey and focus groups. Thank you for being part of this work to improve the system of substance use disorders services.

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C. PROJECT LIMITATIONS

These findings provide a broad snapshot of views but may not reflect the entirety of the United States population with lived experience of substance use.

Our survey relied on a non-probability-based sample recruited through national outreach, and as such, is subject to volunteer bias. In addition, while the project team engaged in targeted outreach, particularly among under-resourced communities, we were not able to recruit a survey sample as diverse as our nation by race, gender, age, and other demographics. We recommend further studies continue to focus on eliciting input from Black, Indigenous and People of Color, lesbian, gay, bisexual and transgender/nonbinary individuals, especially given the disproportionate rates[3] of substance use disorders among these groups, and the legacy of "The War on Drugs" that continues to create inequitable access to quality treatment and services across different races. In addition, our online survey and focus group methodology likely missed the most marginalized, highest need populations, as participation required internet/computer/mobile device access. These project findings are also limited to English speakers—we offered the survey in Spanish but received no responses, and focus groups were conducted only in English.

Our survey was anonymous to protect individual privacy. In order to reach as many people as possible, we did not restrict the number of times the survey could be taken from the same device, so it is possible there were duplicate responses. We also relied on information self-reported by respondents, including about their personal demographic characteristics and experience with substance use disorders.

In addition, we did not ask survey participants to define the "primary" substance associated with their substance use disorder; instead, individuals could select multiple substances that applied to them. We also did not collect information regarding the severity of substance use disorders. It's possible that individuals' desired outcomes change based on their primary substance, and vary over time depending on the severity of their illness. Further research is needed to understand this more fully.

Finally, due to a survey design limitation, respondents could respond "*No*" to the question asking "*Do different results become more important during a pandemic like COVID-19 (coronavirus)?"* and still be prompted to answer the question "*If different results become more important during a pandemic like COVID-19 (coronavirus), what are the top 3 most important results?"* Based on raw data we see some respondents entered different top results during COVID-19 even when they had answered *"No, the three results I chose [pre-COVID-19] are still the most important."* Therefore, our overall finding that 20 percent of people changed what is most important to them during a pandemic could be an underestimate.

3 Hunt, Jerome. "Why the Gay and Transgender Population Experiences Higher Rates of Substance Use." Center for American Progress, 9 Mar. 2012, *www.americanprogress.org/issues/lgbtq-rights/reports/2012/03/09/11228/why-the-gay-and-transgender-population-experiences-higher-rates-of-substance-use/.*

D. DEMOGRAPHICS: SURVEY RESPONDENTS (ANSWERING FOR THEMSELVES = 721)

GENDER	# OF RESPONDENTS	% OF RESPONDENTS	% OF SUD POPULATION**
Woman	408	57%	37%
Man	236	33%	63%
Transgender/Nonbinary	17	2%	*NOT AVAILABLE*
Prefer not to answer/missing	60	8%	
Total	**721**	**100%**	
RACE/ETHNICITY	**# OF RESPONDENTS**	**% OF RESPONDENTS**	**% OF SUD POPULATION****
White	513	71%	66.0%
Black/African American	49	7%	12%
Hispanic or Latino/Latina/Latinx	22	3%	15%
American Indian/Alaska Native	11	2%	0.73%
Asian	1	0.1%	3%
Native Hawaiian/Pacific Islander	4	1%	0.43%
Middle Eastern/North African	2	0.3%	*NOT AVAILABLE*
Multiracial	46	6%	3%
Prefer not to answer/missing	73	10%	
Total	**721**	**100%**	

**from SAMHSA National Survey on Drug Use and Health; SUD in past year among persons aged 18 or older, 2019

AGE (YEARS)	# OF RESPONDENTS	% OF RESPONDENTS
21-30	63	9%
31-45	263	36%
46-64	324	45%
65-75	60	8%
76+	11	2%
Total	**721**	**100**

SOCIOECONOMIC FACTORS	# OF RESPONDENTS	% OF RESPONDENTS
Worried about any of the following: • Food would run out before I got money to buy more • Losing housing or being homeless • Finding, or losing, a job • The electric, gas, water, oil, or internet company threatened to shut off services where I live	298	41%
None of the above	347	48%
Prefer not to answer/missing	76	11%
Total	**721**	**100.0**

E. ALL SURVEY RESPONSES (N=839) BY STATE/TERRITORY

ALL SURVEY RESPONDENTS, INDIVIDUALS RESPONDING FOR SELF AND FAMILY MEMBER EXPERIENCES

*no respondents indicated they were from North Dakota or South Dakota.

STATE*	# OF RESPONSES
ALABAMA	2
ALASKA	14
ARIZONA	2
ARKANSAS	2
CALIFORNIA	31
COLORADO	27
CONNECTICUT	32
DELAWARE	1
FLORIDA	21
GEORGIA	43
GUAM	2
HAWAII	6
IDAHO	7
ILLINOIS	19
INDIANA	8
IOWA	2
KANSAS	1
KENTUCKY	13
LOUISIANA	3
MAINE	11
MARYLAND	34
MASSACHUSETTS	42
MICHIGAN	16
MINNESOTA	19
MISSISSIPPI	7
MISSOURI	7
MONTANA	4
NEBRASKA	4
NEVADA	8
NEW HAMPSHIRE	27
NEW JERSEY	24
NEW MEXICO	4
NEW YORK	24
NORTH CAROLINA	21
OHIO	13
OKLAHOMA	4
OREGON	12
PENNSYLVANIA	37
RHODE ISLAND	7
SOUTH CAROLINA	7
TENNESSEE	17
TEXAS	39
UTAH	9
VERMONT	9
VIRGINIA	29
WASHINGTON	10
WASHINGTON, D.C.	6
WEST VIRGINIA	48
WISCONSIN	13
WYOMING	3
SUB TOTAL	**751**
NO STATE SELECTED	88
TOTAL	**839**

F. DEMOGRAPHICS: FOCUS GROUP PARTICIPANTS

AGE

AGE RANGE	COUNT	PERCENT
21-30	13	25%
31-45	18	34%
46-64	19	36%
65-75	3	6%

GENDER

GENDER	COUNT	PERCENT
Androgynous	1	2%
Man	17	32%
Nonbinary	2	4%
Transgender man	1	2%
Woman	32	60%

RACE/ETHNICITY

RACE	COUNT	PERCENT
American Indian or Alaska Native	7	13%
Asian	2	4%
Black or African American	9	17%
Hispanic or Latino, Latina, Latinx	3	6%
White	35	66%

STATE

STATE	COUNT
Alabama	2
Colorado	1
Connecticut	2
Florida	3
Georgia	1
Idaho	1
Illinois	1
Kentucky	4
Louisiana	3
Maine	1
Maryland	2
Massachusetts	1
Mississippi	1
Missouri	2
Nevada	1
New Hampshire	1
New Jersey	2
New York	1
North Carolina	3
Ohio	1
Oklahoma	1
Pennsylvania	4
Rhode Island	2
South Carolina	2
South Dakota	1
Tennessee	2
Texas	3
Utah	1
Virginia	1
Wisconsin	1

G. DEMOGRAPHICS: NATIONAL PEER COUNCIL MEMBERS

- California
- Georgia
- Massachusetts
- Michigan
- New Jersey
- New Mexico
- New York
- Oklahoma
- Utah
- Virginia

AGE RANGE (YEARS)	NUMBER
21-30	2
31-45	5
46-64	3
65-75	0

RACE/ETHNICITY	NUMBER
Asian	0
American Indian or Alaska Native	3
Black or African American	2
Hispanic or Latino, Latina, Latinx	4
Middle Eastern or North African	0
Native Hawaiian or Pacific Islander	0
White	4