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Capacity Building for Patient Engagement in PCOR on the Effective Use of Telehealth in SUD Treatment: Recommendations

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Executive Summary

What This Project Adds

This project, *Capacity Building for Patient Engagement in PCOR on the Effective Use of Telehealth in SUD Treatment*, reaffirms and contextualizes long-recognized principles of equitable engagement in health research. Focusing on Black individuals with lived experience of substance use disorder (SUD) in the Appalachian region, the project illustrates how existing engagement practices can be deepened, adapted, and sustained when approached through a capacity-building lens. Rather than generating entirely new knowledge, it offers insight into what it takes to translate well-established engagement ideals into reality—particularly within communities historically excluded from research and in the emerging context of telehealth. By grounding these lessons in a specific geographic and sociocultural setting, the project contributes to the growing body of work that seeks to operationalize equity in patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).

Why This Project Matters

Black communities remain underrepresented in both SUD treatment and the research that informs it, despite facing disproportionate harm and systemic barriers to recovery. In Appalachia, where care is shaped by geographic isolation, economic hardship, and persistent racial inequity, these challenges are particularly acute. At the same time, telehealth is rapidly transforming how care is accessed. Without intentional community engagement, however, digital health innovations may further marginalize those already left behind. This project matters because it provides researchers, institutions, and funders with grounded insight into how to build lasting and meaningful partnerships with Black individuals with lived experience, partnerships that are essential to improving the impact that research has.

What We Learned

Through qualitative interviews, the formation of a Patient Advisory Group (PAG), structured convenings, and sessions with researchers, the project surfaced themes that echo and elaborate on prior literature and community experience. Fostering trust was foundational. Both community members and researchers named the importance of creating sustained relationships and a commitment to shared ownership and transparency as ways to build trust, which they agreed could not be secured through transactional approaches or time-limited grants.

The project clarified that effective engagement requires effort: readiness, support, and the creation of conditions in which mutual learning can take place. Participants also emphasized that digital solutions like telehealth have tremendous potential to improve needed care but fall short when they are not culturally responsive, technically accessible, or integrated into systems of care that reflect their lived realities.

What We Recommend

We recommend that engagement be treated not as a discrete element of research but as a long-term, shared commitment. Institutions should invest in structures—such as well-supported Patient Advisory Groups and the role of trusted "community connectors"—that enable sustained dialogue and co-leadership. Researchers require institutional backing, adequate time, and training in trauma-informed, culturally responsive methods to engage with integrity. Community members need access, preparation, and compensation that honors their expertise and time. Funding mechanisms must evolve to allow for engagement before, during, and after the life of a single study. While the focus of this work is on telehealth and SUD, the recommendations apply more broadly, offering practical guidance for embedding the voices of all patients, including those from historically marginalized communities, into all stages of research design and implementation.

Introduction

Background and Context

Substance Use Disorder (SUD) continues to pose significant public health challenges in the United States (U.S.), with racial disparities in its impact and treatment access remaining a critical concern. According to the 2023 National Survey on Drug Use and Health, approximately 17.1% of individuals aged 12 or older (about 48.5 million people) experienced a SUD in the past year, including 28.9 million with alcohol use disorders and 27.2 million with drug use disorders; some individuals had both.[1][2]

During the implementation of this project, the U.S. recorded an estimated 107,543 drug overdose deaths in 2023, with over 81,000 attributed to opioids.[3] This tragic toll highlights the urgency of addressing SUD and its consequences, particularly in Black communities, where disparities are especially pronounced. For example, recent data continue to highlight significant racial disparities in drug overdose death rates in the U.S. In the last year, the overall drug overdose rate for older Black men increased nearly fivefold from 2015, with the death rate for Black men aged 55 and older nearly triple the national average for that age group.[4] Additionally, in the second half of 2023, while White individuals experienced a 14% decline in opioid death rates, declines in other racial and ethnic groups were much smaller, indicating persistent disparities.[5] These trends underscore the ongoing need for targeted interventions to address the unique challenges faced by these populations.

> “Substance use is anything that makes your life unmanageable…after a certain point, you get to where you're really using against your will. You don’t want to, but now your body is craving it. Your mind is craving it. You’ve been doing it for so long that it feels like you can’t live without it…but I was introduced to a new way of life. I'm working in this profession now and learning what 'substance use disorder' really means.

Telehealth has emerged as a critical tool for expanding access to care and offering new opportunities to reach individuals with SUD who face geographic, financial, or systemic barriers to treatment. Despite its potential, the effectiveness of telehealth for SUD treatment, particularly for Black individuals, remains understudied. From some early research, it became evident that Black patients were more likely to seek

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[1] Substance Abuse and Mental Health Services Administration. 2023 National Survey on Drug Use and Health. Accessed January 2024. https://www.samhsa.gov/data

[2] many people with a substance use disorder also have an alcohol use disorder, so they're counted in both subcategories but only once in the total SUD number.

[3] Centers for Disease Control and Prevention. Drug Overdose Deaths in the United States, 2023. Accessed January 2024. https://www.cdc.gov

[4] Word in Black. Black drug overdose deaths rise as disparities persist. Published January 2025. Accessed January 2025. https://wordinblack.com/2025/01/black-drug-overdose-deaths-rise

[5] Kaiser Family Foundation. Opioid deaths fell in mid-2023 but progress is uneven. Published November 2023. Accessed January 2025. https://www.kff.org/mental-health/issue-brief/opioid-deaths-fell-in-mid-2023

and/or self-report telehealth use compared to White patients in the pandemic.[6] However, challenges persisted in ensuring equitable access to and meaningful engagement with telehealth interventions for Black communities.[7]

Project Goals and Alignment with PCOR/CER Principles

This project addresses critical gaps in research by fostering bi-directional engagement between Black individuals with lived experience of SUD and researchers. It created a framework for culturally responsive, patient-centered approaches, focusing specifically on how telehealth can be leveraged to deliver equitable and effective treatment for SUD. By engaging stakeholders in a collaborative process, the project offers a pathway for empowering historically underserved populations to shape research and treatment strategies that directly impact their health outcomes.

The overarching goal of the project was to establish a sustainable methodology for engaging Black individuals in Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER). The formation of a Patient Advisory Group (PAG), comprised of Black individuals with lived SUD experience, was central to achieving this goal. The PAG offered a structured mechanism for integrating patient input into the research process, enabling participants to provide meaningful contributions in defining research priorities, shaping research questions, and thereby generating outcomes that are culturally relevant and impactful for their communities. This approach reflects PCOR principles of inclusiveness, collaboration, and the prioritization of patient voices.

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[6] Frontiers in Public Health. Racial Disparities in Telehealth Use During the Pandemic. Published 2023. Accessed January 2024. https://www.frontiersin.org

[7] Marcondes FO, Normand ST, Le Cook B, Huskamp HA, Rodriguez JA, Barnett ML, Uscher-Pines L, Busch AB, Mehrotra A. Racial and Ethnic Differences in Telemedicine Use. JAMA Health Forum. 2024 Mar 1;5(3):e240131. doi: 10.1001/jamahealthforum.2024.0131. PMID: 38517424; PMCID: PMC10960201.

Methodology

Target Population and Regional Focus

By specifically targeting engagement with Black individuals in the Appalachian region, this project inevitably encountered broader structural issues in health equity. Appalachia is an area that experiences disproportionately high rates of SUD and significant barriers to treatment. It is characterized by a unique confluence of geographic, cultural, and socioeconomic factors that exacerbate challenges in health care access. These include widespread rurality, persistent poverty, and limited access to resources such as broadband internet and reliable transportation, which are critical for the utilization of telehealth services.[8][9] Factors such as generational trauma, stigma surrounding addiction, and limited availability of health care providers trained in culturally responsive care were also central considerations in the project's design.[10]

The regional focus provided an opportunity to test innovative approaches to engagement in areas where traditional health care delivery methods are often inaccessible. The project leveraged partnerships with local organizations and stakeholders who had deep ties to the community, ensuring that outreach efforts were grounded in trust and cultural competence.[11] This approach not only facilitated meaningful engagement with Black individuals in Appalachia but also demonstrated how community-driven methods can overcome barriers to participation in PCOR/CER.

Overview of Project Phases

The project team[12] executed the work in three distinct phases, each designed to build on the previous one and collectively advance the goal of fostering meaningful engagement between Black individuals with lived experience of SUD and researchers to improve PCOR/CER on telehealth treatments for SUD (see Appendix A - Data Collection and Analysis Methods).

Phase 1: Qualitative Interviews

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[8] Substance Abuse and Mental Health Services Administration. 2023 National Survey on Drug Use and Health. Accessed January 2024. https://www.samhsa.gov/data

[9] Appalachian Regional Commission. Health Disparities in Appalachia: Statistical Reports and Data. Published 2023. Accessed January 2024. https://www.arc.gov

[10] Centers for Disease Control and Prevention. Addressing Racial Disparities in Substance Use Disorder Treatment. Published 2023. Accessed January 2024. https://www.cdc.gov

[11] National Institutes of Health. Social Determinants of Health and Addiction Recovery: A Research Perspective. Published 2023. Accessed January 2024. https://www.nih.gov

[12] Network for Excellence in Health Innovation; Community Catalyst; Black Faces Black Voices; and Tony White, Expert-Consultant

The first phase involved conducting semi-structured qualitative interviews with 20 Black individuals with lived SUD experience, focusing on those residing in the Appalachian region. This phase aimed to:

- Understand participants' views on the use of telehealth for SUD treatment.
- Explore barriers to and motivators for engaging in PCOR.
- Identify factors influencing treatment decisions, including awareness of existing research and perceived relevance of research findings. The data collected during this phase provided valuable insights into the needs, preferences, and perspectives of the target population, forming the foundation for subsequent project activities.

Phase 2: Formation of the Patient Advisory Group (PAG)

Building on findings from Phase 1, the second phase focused on establishing a Patient Advisory Group (PAG) comprising 10–12 Black individuals with lived SUD experience. Key activities included:

- Training PAG members on PCOR principles to ensure their effective participation.
- Developing governance structures, including operating guidelines and roles, to sustain the group's activities.
- Convening PAG members for initial discussions to outline goals and work plans.
- Identifying and recruiting researchers to engage with the PAG, ensuring that their perspectives aligned with the group's objectives.

Phase 3: Patient-Researcher Collaboration and Recommendations

The final phase brought together the PAG and a group of researchers in a virtual convening. The goals of this phase were to:

- Facilitate dialogue between patients and researchers to co-develop research priorities, especially involving the use of telehealth in SUD treatment.
- Identify barriers and opportunities for collaboration in research design and implementation.
- Generate actionable recommendations for sustaining patient-researcher engagement beyond the project period. Feedback from the convening informed the final recommendations and a guidance report, which detailed lessons learned, best practices, and strategies for scaling and sustaining patient engagement structures.

Recruitment and Qualitative Interview Process (Phase 1)

The project implemented a structured recruitment and interview process. This phase aimed to identify participants whose insights could inform the development of culturally responsive telehealth interventions for SUD treatment while addressing barriers to participation.

Recruitment Strategy

The recruitment process relied on community-based outreach and existing networks to identify potential participants. Key recruitment activities included:

- **Community Partnerships**: Collaborations with community groups and local networks helped identify and connect with eligible participants. The community groups we worked with knew individuals who would or might be interested in the project and could connect with them from a place of trust and respect.
- **Targeted Outreach Materials** (see appendix B – Information Flyer): The project team developed a one-page flyer to communicate the study's purpose, goals, and objectives. The team used standardized email templates to support outreach efforts, ensuring consistency in communication.
- **Central Point of Contact**: A designated team member served as the primary contact for interested individuals, managing inquiries, onboarding, and scheduling.

This community-driven approach ensured that recruitment efforts were sensitive to participants' circumstances and effectively reached those whose insights were most critical to the study (See Appendix C – Participants Demographics and Diversity).

Onboarding Process

Once individuals expressed interest in participating, the project engaged them in qualitative interviews to further assess their willingness and ability to participate in the project:

- **Communication Preferences:** Participants were asked about their preferred communication methods to maximize comfort and convenience.
- **Pre-Interview Preparation:** An Interview Subject Information Form (Appendix C – Participants Interview Guide) was shared in advance, allowing participants to review and ask questions. This transparency fostered trust and minimized uncertainty and anxiety.
- **Scheduling and Accessibility:** Participants selected their preferred days and times for the 60- to 90-minute interviews. They were also given a choice between video conferencing or phone calls based on their comfort and access.
- **Interview Logistics:** Interviews were conducted on a secure virtual platform to ensure privacy and consistency.
- **Ethical Considerations and Participant Support:** This process prioritized ethical integrity, accessibility, and trust-building, ensuring Black individuals with diverse experiences of SUD could participate comfortably, be fairly compensated, and shape the project's outcomes (see Appendix D – Written Informed Consent Form).

Formation and Governance of the Patient Advisory Group (PAG) (Phase 2)

The second phase of the project focused on the formation and governance of the PAG, which was the vehicle for fostering bi-directional engagement between Black individuals with lived experiences of SUD and researchers. The establishment of the PAG followed a structured approach to ensure inclusivity, effectiveness, and sustainability.

Identification of PAG Members

The project team enlisted Patient Advisory Group (PAG) members from the pool of individuals who had participated in qualitative interviews during Phase 1 of the project. The selection process focused on engaging individuals whose experiences could provide diverse perspectives and meaningful contributions, prioritizing a match with the following criteria:

- **Geographic Representation:** contribution to the diversity of the Appalachian region to ensure that perspectives from multiple counties and communities were included.
- **SUD Experience:** variations in personal lived experience with SUD, encompassing different recovery pathways, such as long-term treatment programs, outpatient services, or peer-led recovery groups.
- **Demographic Diversity:** a balance of gender, age, and socioeconomic backgrounds.
- **Advocacy Potential:** inclusion of candidates who expressed interest in using their experiences to advocate for systemic change or improve health care outcomes for their communities.

This process emphasized transparency and inclusion by evaluating candidates based on their alignment with the criteria and clearly communicating the PAG's objectives and expectations. Efforts were made to address logistical barriers, including the provision of stipends, childcare support, transportation assistance, and flexible scheduling to accommodate personal responsibilities. This intentional, community-centered approach ensured that the PAG was diverse, representative, and well-prepared to provide valuable guidance throughout the project.

Training and Capacity Building

To enable meaningful engagement in Patient-Centered Outcomes Research (PCOR), PAG members underwent a series of training sessions led by project team, focused on:

- **PCOR Principles**: These sessions covered the fundamentals of PCOR, including its objectives, methodologies, and the importance of patient engagement.
- **Roles and Responsibilities**: Members were introduced to their roles within the PAG, including their contributions to co-developing research priorities, shaping methodologies, and evaluating outcomes.
- **Facilitation Skills**: Training included guidance on how to effectively communicate and collaborate with researchers, fostering equitable dialogue and decision-making.

Governance Structures

The governance of the PAG was designed to promote sustainability and ensure clarity in its operations. The project team and PAG members implemented the following components:

- **Operating Guidelines:** A detailed set of guidelines was developed, outlining the group's mission, objectives, roles, and decision-making processes.
- **Collaborative Leadership Model:** The group operated under a shared leadership approach, where all members were encouraged to contribute equally to discussions, decision-making, and task allocation. This model fostered a sense of ownership and ensured that diverse perspectives shaped the group's outputs.
- **Consensus-Based Decision-Making**: The group adopted a collaborative approach to decision-making, ensuring all members had equal opportunities to contribute.

Convening and Collaboration

The PAG's initial operations focused on a series of discussions to establish its goals and work plans. These convenings included:

- **Goal-setting sessions**: Members identified priority areas for research and patient engagement in telehealth-based SUD treatment.
- **Team-Building Activities:** The PAG engaged in exercises to foster trust, build relationships among members, and establish a collaborative dynamic, ensuring a strong foundation for future work.
- **Ongoing Communication**: Members established a schedule for regular meetings and check-ins to maintain momentum and address emerging challenges. Over the course of the second phase, the PAG convened six times, including a full-day, in-person gathering held in Pittsburgh, PA—a centrally located venue selected to accommodate members from across the Appalachian region. This in-person gathering played a crucial role in strengthening relationships and deepening engagement.

Structured Convening Between PAG and Researchers (Phase 3)

The formation of the PAG set the stage for a series of thoughtfully facilitated convenings that were essential to achieving the project's objectives. To ensure researchers were prepared to engage equitably and effectively with PAG members, the project team first organized a series of researcher-only meetings. These sessions focused on building foundational knowledge about engagement practices in this project, unpacking power dynamics in research, and preparing for authentic, community-centered dialogue. Researchers also reviewed project goals and ethical considerations and worked together to align on principles for collaboration. These meetings created a critical space for reflection and skill-building, ensuring researchers entered joint sessions with the PAG ready to listen, learn, and share power.

Based on feedback from both researchers and PAG members, the project team then employed a hybrid approach, combining virtual and in-person sessions. Each convening spanned two days, with carefully planned agendas to balance information sharing, discussion, and collaborative activities.

Key features of the structure included:

- **Opening Sessions:** Introductions and icebreakers fostered a sense of community and set the tone for open dialogue.
- **Panel Discussions:** Experts (researchers) shared insights on telehealth and SUD treatment, grounding the discussions in evidence and real-world applications.
- **Breakout Groups:** Small group discussions allowed for deeper exploration of specific topics and encouraged all voices to be heard.
- **Interactive Workshops:** Participants engaged in hands-on activities, such as co-creating research priorities and refining engagement models.
- **Closing Sessions:** Summaries of discussions and next steps ensured alignment and clarity.

Key Themes: Qualitative Interviews and Patient Advisory Group Sessions

The voices of Black individuals in the Appalachian region with lived experiences of SUD, as shared during in-depth interviews, illuminate the systemic barriers they face, the critical importance of cultural relevance in treatment, and their desire for a future shaped by equity and understanding.

Amplifying Voices: The Power of Being Heard

Participants consistently emphasized how much it meant to be invited to share their experiences. For many, this was the first time anyone had shown interest in their journey, their struggles, and their resilience. “It makes my heart just so happy that people are wanting to do stuff like this. And care about the treatment of Black people. Because it’s different. It just makes me so happy,” one participant remarked, encapsulating the sentiment of many. This appreciation was matched by a desire to see their voices make a tangible impact. Participants expressed eagerness to be involved in future research phases by advocating for transparency and following through with researchers. As one individual said, “Don’t be afraid to ask the hard questions. You know, get to the real gritty.” Three key issues emerged as barriers to involvement in research on telehealth treatments for SUDs:

- **Mistrust of institutions:** Historical inequities and experiences with systemic racism continue to contribute to skepticism toward health care and research efforts.
- **Technological hurdles:** Limited internet access and digital literacy impede the adoption of telehealth service
- **Underrepresentation:** A lack of Black professionals in recovery services and research roles perpetuates feelings of alienation.

> “I think they should have a clearer understanding of when it suffices to use telehealth. Just because we have the option to, I don't think it should always be the answer. Someone's mental state—someone's using state—you can see more in person. So, I think doctors and professionals should assess the situation a little better, just because it's an option, you don't gotta use it.

The interviews revealed deep-seated mistrust of health care and research institutions, often rooted in historical inequities. Participants described feeling overlooked in treatment and recovery systems, with one noting, "How many Black women do they actually get offered drug court? I never even heard of it until I started working in this field." Telehealth offerings did not negate feelings of mistrust and marginalization. In some ways, these highlighted disparities in internet access and comfort with technology. Additionally, telehealth did not overcome the lack of culturally competent care; providers involved in providing telehealth still left many feeling misunderstood and unsupported.

Opportunities: Building Bridges Through Community

Despite these challenges, participants identified promising pathways to strengthen engagement and improve outcomes. Trusted community resources, such as faith-based organizations and local leaders, were seen as vital bridges for outreach and engagement.

Participants also emphasized the importance of culturally tailored approaches that represent an understanding of patients' circumstances. "Recovery isn't just about stopping the use. It's about feeling understood and supported in who we are and where we come from," one participant explained. Others emphasized the need to integrate lived experiences into care models, advocating for peer-recovery specialists and relatable role models to play a more central role in treatment and research initiatives.

Opportunities for improvement included:

- **Leveraging trusted networks:** Collaborating with faith-based organizations and community leaders to enhance outreach.
- **Integrating lived experiences:** Centering care models around peer-recovery specialists who understand the realities of SUD.
- **Enhancing cultural competence and representation in research design:** Tailoring interventions to reflect the unique cultural dynamics of Black communities and involving peer recovery specialists and other relatable role models in the design and delivery of research and care.

> "There need to be more people who look like you reaching out into the community. Sometimes it's not as comfortable when people don't look like you or don't come from where you come from. So, it's always good to see someone who's been through what you've been through—it hits in a different dynamic.

Insights into Telehealth: Mixed Reactions

Opinions on telehealth services varied. While some participants appreciated its convenience and accessibility, others expressed hesitations about its effectiveness compared to in-person care. For those unfamiliar with the term, telehealth was often reframed as "telephone recovery," which better resonated with their experiences.

Positive reflections included the ability to maintain consistent contact with therapists and the flexibility telehealth offers for those with transportation or childcare challenges. However, others noted a lack of personal connection and questioned its adequacy for addressing complex emotional needs.

> I liked it because I didn't have to worry about ever seeing them in person. But the downside was the lack of connection because we're talking on the phone.

Criminal Legal System: A Critical Touchpoint?

A recurring theme in participants' narratives was the significant—yet often troubling—role of the criminal legal system in shaping their treatment journeys. Many described being introduced to treatment only after arrest, incarceration, or as a condition of probation or parole. For some, these court-mandated programs were their first exposure to recovery. While this underscores the system's far-reaching influence, it also raises serious concerns about equity, autonomy, and the structural pathways into care.

This intersection reveals a troubling reality: systems of punishment have become default entry points for treatment. As one participant shared: "The criminal justice system... I continued to get incarcerated and put on probation. And I noticed that every time I did, I was under substance use. It became a pattern, so I thought maybe the substances, along with me, could be the problem." This quote reflects a moment of self-awareness shaped by repeated system contact—but also highlights how care remained reactive, punitive, and delayed. Rather than being offered treatment through supportive health or community systems, treatment was often only encountered as a consequence of criminalization.

Recommendations and Implications for Future Engagement

Participants offered actionable recommendations to increase community engagement in research and improve the effectiveness of telehealth interventions. They called for:

- **Fair compensation:** Ensuring participants feel valued for their time and insights through appropriate stipends.
- **Representation in research:** Recruiting Black researchers and facilitators to foster trust and relatability.
- **Community-based outreach:** Advertising opportunities to shape and participate in research in spaces familiar to Black communities, such as churches, barbershops, and local events.

Additionally, participants stressed the importance of follow-up and transparency. Many had previously participated in research but felt disillusioned when they received no updates on its outcomes. “It kind of bothers me that sometimes you don’t see the outcome of the research project. Now, what are you going to do with it?” one individual asked. The interviews illuminated the need to center Black voices in research and health care delivery. By addressing systemic barriers, fostering trust, and prioritizing cultural relevance, we can create more equitable and effective SUD treatment models. As one participant eloquently put it, “I just want to give back. I want people to have what I got from it. This is the perfect platform.”

> I hope to gain more knowledge on resources and what is needed in the black community dealing with recovery so I'm able to take that for myself and also like give that to other people who are black and brown people.

Key Themes: Researcher Interviews and Research-only Sessions

In our conversations with researchers and through research-only sessions, a recurring theme emerged—while the value of engaging persons with lived experience in SUD is widely acknowledged, significant barriers prevent meaningful and sustained collaboration.

Throughout these discussions, researchers described how their time and funding are primarily allocated to specific research studies, leaving little flexibility for engagement beyond the confines of structured projects. Without dedicated resources, opportunities for organic relationship-building and long-term collaboration remain scarce. Many researchers want to engage more but simply do not have the structural support to do so.

Those who have managed to overcome these challenges often cited institutional support as a critical factor. When backed by their academic institutions—whether through administrative resources, funding for engagement efforts, or formalized partnership structures—they found it far easier to create meaningful connections with individuals who have lived experience. Researchers in institutions with strong engagement infrastructures reported more success in developing trust and co-developing research agendas that were informed by community priorities. However, those lacking this support often struggled to move beyond tokenistic engagement.

Yet, even when structural barriers were addressed, a deeper issue remained. Many researchers admitted to feeling uncertain or even uncomfortable about how to engage with persons with lived experience in SUD. Some were concerned about unintentionally causing harm or failing to establish genuine, mutually beneficial relationships. Others lacked training in trauma-informed approaches and worried about how to navigate sensitive conversations.

The solution, many suggested, lay in having a dedicated connector[13]—someone embedded in the community who could help bridge the gap between research institutions and individuals with lived experience. These intermediaries, whether individuals or trusted community organizations, would play a crucial role in ensuring that engagement efforts were not only ethical but also effective. A community connector could provide insight into lived experience perspectives, facilitate relationship-building, and help researchers create spaces that feel safe, inclusive, and respectful. Taken together, these reflections point to a clear need: sustainable, ethical engagement requires both structural investment and relational infrastructure.

Without intentional support, from institutions, funders, and community partners alike, the promise of truly co-created research with people with lived experience in SUD will remain out of reach. Bridging this gap is not only a matter of logistics, but a matter of equity and trust.

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[13] an individual embedded in the community who is trusted, culturally fluent, and capable of navigating both research protocols and lived experience. These connectors may come from peer recovery networks, faith-based institutions, or advocacy groups, and are critical in building trust, supporting recruitment, and ensuring accountability

Key Themes: Structured Convening Between PAG and Researchers

The structured convenings between the PAG and researchers resulted in several actionable outcomes. These outcomes revolved around three key areas: research priorities, engagement models, and capacity building. Collectively, they highlight the transformative potential of patient-centered collaboration in advancing equity and effectiveness in telehealth for SUD treatment.

Research Priorities

Participants identified critical areas for future investigation that address both the systemic barriers and unique needs of Black communities in using telehealth to treat SUDs. These priorities include:

- **Assessing the Effectiveness of Telehealth for SUD Treatment:** Participants stressed the need for rigorous studies that produce evidence-based recommendations on the effective use of telehealth to meet the specific needs of Black individuals.
- **Developing Strategies for Improving Access:** Accessibility challenges, such as lack of reliable internet, limited digital literacy, and financial barriers, were recurring themes in the discussions. Research priorities included exploring innovative solutions to bridge the digital divide and enhance access for underserved populations.

- **Highlighting the Impact of Social Determinants of Health:** Recognizing the interplay between social factors—such as housing, employment, and community support—and health outcomes, participants emphasized the need for research that examines these connections. They advocated for studies that address environmental barriers to holistic recovery pathways and promote holistic recovery pathways to supplement clinical interventions.

Integration of Community Insights Through Sustained Relationships

The convenings emphasized that meaningful engagement requires both the integration of lived experiences into research design and the cultivation of long-term, trust-based relationships. Participants stressed that one-time consultations are insufficient to fully reflect community realities. Instead, building and sustaining relationships between researchers and communities over time was seen as essential to ensuring research remains grounded, relevant, and equitable. Researchers, most especially, recognized the importance of forming deeper relationships with people with lived experience in SUD—not only to guide their research priorities but also to enrich the overall quality and impact of their work. To support this, both PAG members and researchers highlighted the importance of:

- **Iterative Feedback Loops:** Mechanisms for continuous feedback throughout and after the research process ensure that community voices remain central and involved beyond the scope of individual projects.
- **Equitable Power-Sharing:** Transparent communication, shared leadership, and valuing lived experience alongside formal expertise were key recommendations for rebalancing traditional power dynamics.
- **Relational Infrastructure:** Sustained engagement was seen as both a strategy and a value—one that supports long-term impact, trust, and alignment with community-defined priorities.

Building Collective Capacity

One of the most significant outcomes of the convenings was the mutual capacity-building that occurred among participants. Both researchers and PAG members reported gaining valuable skills and perspectives that will enhance their ability to collaborate effectively in future projects:

For Researchers

- Improved cultural competence through direct engagement with PAG members.
- Enhanced understanding of the systemic barriers impacting Black communities.
- Greater appreciation for the importance of patient-centered approaches in research.

For PAG Members

- Increased confidence in articulating their experiences and advocating for systemic change.
- Familiarity with research methodologies and the role of patient engagement in shaping outcomes.
- Strengthened networks with other community members and researchers, fostering a sense of collective purpose.

Broader Implications

These outcomes extend beyond the immediate scope of the convenings, offering a promising foundation for future initiatives. By aligning research questions with community insights, fostering meaningful dialogue, and cultivating mutual capacity, the project has contributed to a model for strengthening patient-centered collaboration in health care research—particularly in work involving complex and diverse populations. Although this project was limited in time compared to its ambitions, it identified key elements that can improve the conditions for inclusive and patient-centered research. The lessons learned below offer guidance for designing future efforts that are grounded in trust, accountability, and ongoing partnership.

> “This isn’t just about telehealth or SUD. It’s about showing that when you work with us, not for us, you can create real change.

Lessons Learned

This project provided valuable insights for fostering effective collaborations between patients and researchers. Below, we offer the reflections of the project team on the challenges encountered and the strategic adjustments made in response.

The Project Team's Consensus on Challenges and Successes

From the outset, the project team recognized that embarking on a patient-centered research initiative of this scope would require navigating a series of logistical and relational complexities. One of the most significant challenges was coordinating the diverse needs and schedules of the PAG members and researchers. The hybrid format of convenings—a necessity due to geographical and technological barriers—introduced additional layers of complexity.

A related challenge lay in building trust among stakeholders, particularly given the historical context of mistrust in research among Black communities. The team understood that this was not a hurdle to be cleared quickly but a process requiring ongoing transparency, active listening, and a commitment to addressing systemic inequities. Early missteps, such as underestimating the time needed for relationship-building, underscored the importance of prioritizing trust as a foundational element of the project.

As referenced earlier, the project team addressed these challenges by adjusting its plans. Originally, the project called for two meetings with the PAG and a single joint convening with PAG members and researchers. However, it quickly became clear—through conversations with both groups—that this structure would not support meaningful dialogue. With the assent of stakeholders, the team adjusted the plan to include additional PAG sessions, researcher-only sessions, and another joint convening. While it is not possible to draw a direct causal connection between these adjustments and project outcomes, the feedback received suggests that the expanded engagement allowed for the development of a partnership rooted in mutual respect and shared purpose. Together, PAG members and researchers co-developed research priorities, grounding the project in lived experience and ensuring its relevance and actionability.

PAG members expressed gratitude for the opportunity to have their voices heard and to influence the research direction. Researchers, in turn, reported gaining a deeper understanding of the systemic barriers faced by Black communities and the importance of cultural competence in designing effective telehealth interventions.

These successes affirmed the project's approach and laid a strong foundation for future initiatives aiming to bridge the gap between research and community needs.

Key Takeaways for Building Effective Patient-Researcher Partnerships

Partnerships between researchers and those they seek to benefit through their work are necessary to improve the quality and impact of research. Effective partnerships require a commitment to equity, inclusivity, and mutual respect.

Trust is Foundational

This project underscored an observation many others have made, but have struggled to heed: trust between researchers and community participants is essential to an effective collaboration.[14] The project affirmed, however, that trust cannot be built transactionally in connection with a single research endeavor. It must be fostered over time and sustained to identify and confront challenges faced by particular communities.[15] For the PAG members, trust was cultivated through consistent engagement, honest communication, and tangible demonstrations of respect for their lived experiences—including active listening, open and honest interchanges, and a willingness to adjust plans based on PAG feedback. Researchers who embraced this ethos found that their relationships with PAG members deepened, enabling richer and more meaningful exchanges.

The project also highlighted the importance of acknowledging and addressing the power dynamics inherent in research. By creating spaces where PAG members felt comfortable sharing their perspectives without fear of judgment or dismissal and confirming what we heard, the project team fostered a sense of psychological safety. This, in turn, enabled more authentic and impactful collaborations.

Cultural Sensitivity Must Be Sought and Gained

PAG members consistently underscored the need for interventions that resonate with their lived experiences and address the systemic barriers they face. They want researchers to engage deeply with the social, historical, and cultural realities of the communities they seek to serve. Training sessions on cultural awareness, researchers' direct interactions with PAG members, even in the context of this time-limited project, demonstrated the value of building this understanding. Researchers who approached the convenings with a genuine desire to exchange perspectives found that they were able to co-create solutions that were both innovative and grounded in real-world relevance.

It is also the case, however, that the work the project team did to enhance PAG members' understanding of researchers' circumstances benefited PAG members.

PAG members were able to appreciate the challenges that researchers faced and then felt empowered to develop potential solutions that embraced both their own circumstances and those that researchers faced. Researchers' honesty regarding their own concerns further enabled real dialogue and relationships.

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[15] Lansing AE, Romero NJ, Siantz E, Silva V, Center K, Casteel D, Gilmer T. Building trust: Leadership reflections on community empowerment and engagement in a large urban initiative. BMC Public Health. 2023;23(1):1252. doi: 10.1186/s12889-023-15860-z. PMID: 37379199; PMCID: PMC10304389.

Collaboration Drives Impact

Perhaps the most powerful lesson from this project is that collaboration is the key to driving meaningful and lasting impact. When researchers and patients come together as equal partners, the outcomes are richer, more relevant, and more actionable. The co-creation of research priorities during the convenings is a prime example of this dynamic. Researchers expressed greater confidence that their work would find resonance and achieve impact by integrating PAG insights into their research designs.

Collaboration also enhances the sustainability of patient engagement efforts because it creates a sense of joint ownership, creating a foundation for ongoing partnerships and continued advocacy. PAG members expressed a strong desire to remain involved in future initiatives, viewing their participation not just as a contribution to a single project but as part of a broader movement to advance equity in health care research and practice.

Sustainability and Recommendations

The need for sustainable relationships between researchers and community members is evident, especially in the case of research affecting marginalized communities. Research on the impact of telehealth in treating SUD in marginalized communities adds significant complexity; telehealth relies on multiple environmental factors and adds into the mix the importance of individual skills by both the clinician and the patient. Stigma and the variety of conditions encompassed by SUD complicate matters further. That said, we doubt our findings are confined to this category of research. Dealing with this topic, however, has made certain recommendations more obvious and urgent. In sharing the project team's insights below, we nevertheless acknowledge that further thought and engagement by both researchers and community members is vital to testing and refining them.

Structuring Engagement Outside of Specific Research Projects

The sustainability of patient engagement lies in institutionalizing mechanisms that ensure continuity beyond the lifespan of individual projects. This requires recognizing that resources are needed to create and maintain structures and processes that build relationships and maintain relevance for all stakeholders.

The learnings from this project, combined with insights from related initiatives, emphasize a multi-pronged approach to embedding patient and community voices into systemic practices, ensuring their influence extends beyond episodic engagements.

Creating Long-Term Advisory Structures

Advisory groups, such as the PAG developed in this initiative, represent an important component of fostering ongoing collaboration. These groups provide a consistent platform where individuals with lived experience can engage with researchers, share insights, and shape priorities. Nevertheless, a PAG is not self-sustaining. Long-term success requires institutional commitment and infrastructure. Health care and academic institutions—particularly those that benefit most from the research—will need to take responsibility for supporting and sustaining these advisory groups. Although they may also argue that their resources are limited, they remain in the best position to secure funding from public and private research funders. While community-based organizations may play a critical role in supporting PAGs, they are unlikely to have the resources and capacity to sustain them. Importantly, sustaining institutions must also ensure the autonomy of PAGs, protecting their ability to offer honest, critical, and independent input without fear of co-optation or tokenization.

Strengthening Community Partnerships

Although community-based organizations may not be able to sustain a PAG, or similar structure, it remains vital to ensure that community-based organizations, such as peer recovery networks, churches, and local advocacy groups, are engaged in establishing and supporting a PAG. These organizations act as trusted intermediaries, helping to bridge gaps in understanding and access. Sustained engagement requires formal partnerships that include regular communication, co-hosted events, and shared leadership roles to maintain trust and foster mutual accountability. For example, partnerships with faith-based organizations in the Appalachian region significantly enhanced the project's ability to recruit participants and gather culturally relevant insights. Strengthening the ties between academic and health care institutions committed to research for the purpose of advancing equitable and impactful research, must be a focus of improving community engagement.

Securing Dedicated Funding Streams

A critical challenge in sustaining engagement is securing consistent funding. Advocacy for earmarked resources to support community partnerships, advisory groups, and cultural competency training is essential.

This commitment must extend to compensating participants for their time and expertise, ensuring that engagement is equitable and reflective of its intrinsic value. Without this financial support, patient engagement efforts risk becoming fragmented and unsustainable.

Structuring Engagement Within Specific Research Projects

Integrating individuals with lived experience into the lifecycle of research projects is transformative, shifting the paradigm from researcher-led initiatives to co-created processes. The findings of this project, supported by the experiences of PAG members, highlight the critical elements of effective engagement.

Embedding PAGs Across Research Phases

PAG involvement from the earliest stages of project design ensures that research priorities are relevant and community driven. For example, PAG members in this project directly influenced the framing of research questions, ensuring cultural and contextual appropriateness. Their continuous engagement through data collection, analysis, and dissemination allows for iterative feedback and adaptive strategies that reflect the evolving needs of the study population.

Clear Roles and Transparent Expectations

Ambiguity in roles can undermine trust and effectiveness. Explicitly defining the contributions of PAG members, researchers, and other stakeholders fosters mutual respect and accountability. This clarity extends to the delineation of decision-making processes, timelines, and goals, creating a shared understanding of responsibilities.

Addressing Participation Barriers

Barriers such as digital access, scheduling conflicts, and language differences can impede meaningful engagement. Proactively addressing these challenges is paramount. Strategies like providing pre-engagement training, offering flexible meeting options and childcare, and using culturally relevant communication tools help to ensure that participation is inclusive and representative.

Iterative Feedback and Shared Ownership

Building a culture of feedback within research projects creates a collaborative dynamic where PAG members feel heard and valued. This practice not only improves project outcomes but also enhances participants' trust in the process. Sharing interim findings and seeking input before finalizing conclusions exemplifies necessary respect for community voices to enable effective engagement.

Recommendations for Future Action: Building Momentum for Sustainable Change

The findings from this project highlight the need for sustained and intentional actions to ensure the long-term success of patient engagement efforts, particularly in applications for SUD treatment, which increasingly implicate telehealth. Drawing from both the insights gained during this initiative and the broader body of research on community engagement in health care, we offer several actionable recommendations.

Institutionalizing PAGs and Advisory Groups

Patient Advisory Groups, and similar community groups dedicated to engaging in research, have demonstrated promise in improving patient engagement in all phases of the research process. By institutionalizing these groups as permanent fixtures within research and health care organizations, their influence can extend beyond individual projects, embedding patient perspectives into the fabric of decision-making processes. This approach aligns with findings from similar PCORI/CER initiatives, which emphasize the value of sustained patient engagement in enhancing the relevance and impact of research outcomes.[16] Studies demonstrate that institutionalizing PAGs leads to improved patient-centered care and more effective interventions. For example, the use of advisory groups in designing telehealth solutions has been linked to higher patient satisfaction and better adoption rates, as patients feel their unique needs are being directly addressed.[17] Additionally, embedding these groups into organizational structures ensures that community voices remain a central component of health care innovation. PAGs focused on telehealth are especially important to provide insights into technological and cultural barriers, ensuring that telehealth solutions for SUD are accessible, user-friendly, and aligned with patient needs.[18]

Investing in Training and Collaborative Skills Development

Effective collaboration between researchers and community members requires targeted training and collaborative skills development efforts, especially to enhance relational skills within and between researchers and marginalized groups. This project highlighted the importance of cultural awareness and shared decision-making in fostering trust and mutual respect.

Training programs should focus on equipping researchers with the skills needed to engage diverse populations meaningfully while empowering community members to contribute confidently to research discussions.

Comprehensive training not only improves communication but also ensures that both researchers and community members have a shared understanding of project goals and methodologies. Research shows that training programs emphasizing cultural sensitivity and competence result in more equitable health care outcomes. For instance, health care professionals who participated in cultural competence training were better equipped to address disparities in treatment outcomes among marginalized groups.[19] By incorporating modules on telehealth, these programs can prepare participants to navigate digital platforms, address technological barriers, and ensure that telehealth interventions are culturally responsive and effective.[20]

Capacity-building efforts should also extend to PAG members, ensuring they have the resources and knowledge needed to participate meaningfully. This includes providing training on health care research principles, telehealth technology, and advocacy skills. Empowering community members in this way not only enhances the quality of their contributions but also fosters a sense of ownership and agency in shaping health care outcomes.[21]

Establishing Funding Mechanisms

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[17] Manafo E, Petermann L, Mason-Lai P, Vandall-Walker V. Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. Health Res Policy Syst. 2018;16(1):5.

[18] Greenhalgh T, Vijayaraghavan S, Wherton J, et al. Virtual online consultations: advantages and limitations (VOCAL) study. BMJ Open. 2016;6(1):e009388.

[19] Beach MC, Price EG, Gary TL, et al. Cultural competence: a systematic review of health care provider educational interventions. Med Care. 2005;43(4):356-373.

[20] Kruse CS, Krowski N, Rodriguez B, Tran L, Vela J, Brooks M. Telehealth and patient satisfaction: a systematic review and narrative analysis. BMJ Open. 2017;7(8):e016242.

[21] Wallerstein N, Duran B, Oetzel J, Minkler M. Community-Based Participatory Research for Health: Advancing Social and Health Equity. 3rd ed. Jossey-Bass; 2018.

Research strongly suggests that fostering long-term community trust[22] is essential to ensure that community voices remain integral to health care decision-making.[23] However, sustaining meaningful engagement requires more than goodwill—it requires dedicated, reliable funding. From forming a Patient Advisory Group (PAG) to holding regular meetings, maintaining communications, and providing necessary training, the work is resource-intensive and time-consuming.

To support this work, institutions and funders must expand targeted funding mechanisms specifically designed to support relationship-building with the communities intended to benefit from research. These mechanisms should go beyond project-based grants to provide researchers with sustained support and accountability, including training in trauma-informed and equitable engagement practices. Formalizing and funding community connector roles can further strengthen these efforts by facilitating ongoing, trust-based relationships between researchers and individuals with lived experience.

This project demonstrated how even modest funding, such as compensating participants for their time, can have a powerful impact. Fair compensation not only honors the expertise of those with lived experience but also removes financial barriers to participation. Looking ahead, especially in the context of telehealth research, additional investments may be needed to ensure equitable access. This includes funding for digital infrastructure, such as smartphones or internet access, so that all participants can fully engage in telehealth-focused discussions.

Together, these investments lay the foundation for more inclusive, equitable, and community-driven research.

Fostering Multi-Sector Partnerships

This project demonstrated the value of partnerships with community-based organizations in reaching and engaging participants effectively. Building on this foundation, future efforts should aim to create multi-sector collaborations that integrate perspectives from across the health care ecosystem.[24] Expanding engagement efforts to include policymakers, community organizations, and other stakeholders seems essential to amplify the impact of research and ensure its relevance.

The role of policymakers is particularly important in addressing systemic barriers to telehealth adoption, such as inadequate internet infrastructure or restrictive licensing regulations. Collaborations with technology developers can further ensure that telehealth platforms are designed with user input, enhancing accessibility and usability. Multi-sector partnerships also provide opportunities for knowledge-sharing, enabling stakeholders to learn from each other's experiences and expertise.[25] For instance, partnerships between health care organizations and faith-based groups have been shown to

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[23] Parker MM, Moffet HH, Adams A, Karter AJ. An implementation science approach to telehealth for SUD treatment. Telemed J E Health. 2022;28(5):676-684.

[24] Boaz A, Hanney S, Borst R, O'Shea A, Kok M. How to engage stakeholders in research: design principles to support improvement. Health Res Policy Syst. 2016;14:60.

[25] Brooks E, Turvey C, Augusterfer EF. Provider barriers to telemental health: obstacles overcome, obstacles remaining. Telemed J E Health. 2013;19(6):433-437.

improve outreach and engagement in marginalized communities, leveraging the trust and influence of these organizations to promote health initiatives.[26]

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[26] Chong WW, Aslani P, Chen TF. Shared decision-making and interprofessional collaboration in mental healthcare: a qualitative study exploring perceptions of barriers and facilitators. J Interprof Care. 2013;27(5):378-384.

Conclusion

One of the most significant contributions of this project is the identification of core practices that support meaningful engagement with marginalized communities in research. Rather than offering a one-size-fits-all model, this work elevates conditions and strategies that can be adapted across diverse settings—sustained relationship-building, integration of lived experience across all phases of research, continuous feedback loops, and culturally responsive approaches. By documenting not just the outcomes but the processes, this initiative offers a practical foundation for others seeking to build more inclusive, accountable research practices.

Crucially, the project also highlighted the need for structural support—dedicated funding, institutional backing, and administrative infrastructure—to move engagement beyond one-off consultations. This is especially urgent in telehealth research, where systemic barriers vary across communities. Whether it’s rural areas with limited broadband or urban communities facing digital inequity, strategies must be rooted in community input and adapted to context. That includes everything from platform design to digital literacy efforts and culturally relevant care models.

Though grounded in the context of telehealth and substance use disorder (SUD) treatment, the lessons here carry broader relevance. Early involvement of communities, investment in long-term relationships, and a shift toward power-sharing are not only important strategies, they are preconditions for equity in research.

As patient-centered outcomes research continues to evolve, these insights offer both a call to action and a pathway forward: to build research that is not only effective but just—where trust, shared decision-making, and community voice are centered from the start.

Appendix A: Data Collection and Analysis Methods

Data Collection Process

Qualitative Interviews: The cornerstone of the data collection process was the use of semi-structured qualitative interviews. The project team conducted interviews with 20 Black individuals with lived experience of SUD. These interviews were designed to explore participants' perspectives on telehealth as a tool for SUD treatment, their treatment pathways, and the barriers and facilitators they encountered in accessing care. Questions were open-ended to allow participants to share their experiences in their own words, fostering a deeper understanding of the social and cultural contexts influencing their health outcomes.

Surveys: Pre- and post-engagement surveys were used to complement qualitative methods. These surveys assessed participants' baseline understanding of telehealth, their experiences with patient-centered outcomes research (PCOR), and the perceived relevance of telehealth interventions to their needs. Survey data provided a quantitative lens through which to triangulate findings from interviews and focus groups.

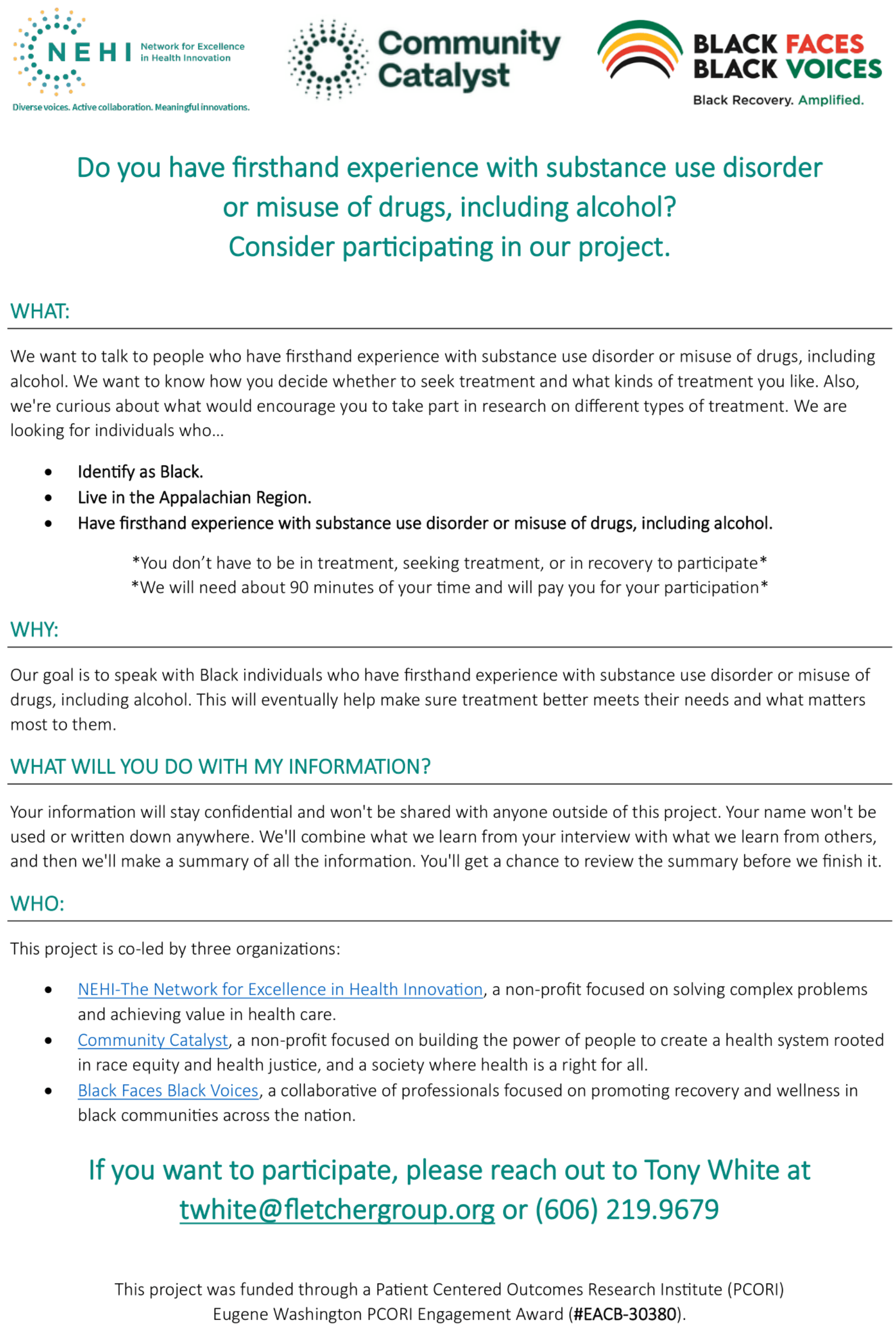
Data Analysis Methods

Thematic Analysis: The project team employed a thematic analysis approach to identify patterns and recurring themes within the qualitative data. Interview and focus group transcripts were reviewed and coded using qualitative analysis software, ensuring a systematic and transparent process. Codes were categorized into themes that reflected participants' experiences, barriers, and opportunities related to telehealth for SUD treatment.

Triangulation: To enhance the reliability and validity of findings, triangulation was used. This involved cross-referencing qualitative data from interviews and focus groups with survey results and external literature. By integrating multiple data sources, the analysis captured a comprehensive picture of the factors influencing telehealth adoption and engagement among Black individuals with SUD.

Participant Validation: Preliminary findings were shared with PAG members and selected participants to validate interpretations and ensure that the analysis accurately reflected their experiences. Feedback from these sessions was incorporated into the final analysis, reinforcing the project's commitment to inclusivity and co-creation.

Appendix B: Information Flyer



Do you have firsthand experience with substance use disorder or misuse of drugs, including alcohol?
Consider participating in our project.

WHAT:

We want to talk to people who have firsthand experience with substance use disorder or misuse of drugs, including alcohol. We want to know how you decide whether to seek treatment and what kinds of treatment you like. Also, we're curious about what would encourage you to take part in research on different types of treatment. We are looking for individuals who…

- Identify as Black.
- Live in the Appalachian Region.
- Have firsthand experience with substance use disorder or misuse of drugs, including alcohol.

You don't have to be in treatment, seeking treatment, or in recovery to participate
We will need about 90 minutes of your time and will pay you for your participation

WHY:

Our goal is to speak with Black individuals who have firsthand experience with substance use disorder or misuse of drugs, including alcohol. This will eventually help make sure treatment better meets their needs and what matters most to them.

WHAT WILL YOU DO WITH MY INFORMATION?

Your information will stay confidential and won't be shared with anyone outside of this project. Your name won't be used or written down anywhere. We'll combine what we learn from your interview with what we learn from others, and then we'll make a summary of all the information. You'll get a chance to review the summary before we finish it.

WHO:

This project is co-led by three organizations:

- NEHI-The Network for Excellence in Health Innovation, a non-profit focused on solving complex problems and achieving value in health care.
- Community Catalyst, a non-profit focused on building the power of people to create a health system rooted in race equity and health justice, and a society where health is a right for all.
- Black Faces Black Voices, a collaborative of professionals focused on promoting recovery and wellness in black communities across the nation.

If you want to participate, please reach out to Tony White at twhite@fletchergroup.org or (606) 219.9679

This project was funded through a Patient Centered Outcomes Research Institute (PCORI)
Eugene Washington PCORI Engagement Award (#EACB-30380).

Appendix C: Participant Demographics and Diversity

The project successfully recruited a diverse group of potential participants. Key characteristics included:

- **Gender:** Eight of the participants were female, and 11 were male (self-identified).
- **Age:** Ages of the participants ranged from their early 20s through their late 60s.
- **Substance(s) use:** Many of the interviewees, through their responses to our questions, described their experience with different substances. Substance(s) of use included cocaine, heroin, methamphetamine, opioids, marijuana, alcohol, among a few others. Importantly, many of the participants included alcohol in their definition of substances that can fall under substance use disorder. The project team also was clear to be as expansive as possible in its definition of substances. All communications and outreach for the project included alcohol.
- **Treatment pathway:** The individuals all had varying experiences with treatment for SUD. Eight of the individuals—all men—were, at the time of the interview, in a residential long-term, social model of recovery program in Kentucky. These individuals had a variety of experiences with treatment, such as with outpatient or intensive outpatient treatment (IOP) programs. Other interviewees had no experience with individualized treatment; they had relied on group programs like Narcotics Anonymous or Alcoholics Anonymous to assist with their recovery.
- **Length of time in recovery:** Every person we spoke with was in recovery at the time of the interview. The length of time that each person had been in recovery varied significantly. Some individuals had been in recovery for a few months at the time of the interview, while others had been in recovery for decades. Many individuals we spoke with said that they had experienced relapse of SUD at various times in their past.
- **Past familial experience with SUD:** Many participants described that they had witnessed or been around SUD or misuse in family members (e.g., parents or siblings).
- **Peer-recovery professionals:** Four of the individuals we spoke with were not only committed to long-term recovery for themselves but were also working in the peer-recovery field. When we spoke with these individuals, we asked them to clarify when they were speaking from their own personal experience with SUD and when they were speaking from their experience as a peer-recovery specialist.
- **Living Situations:** The participant pool included individuals in permanent housing, temporary shelters, and long-term treatment facilities.

Appendix D: Participants Interview Guide

Welcome

Before we start, here are a few things to know:

- Our call will last for about 60 to 90 minutes.

- We will be recording this session and writing down what we talk about. But don't worry, we won't use your name or anything like that in our reports. If you don't want to be recorded, you can let us know now, and we will end the interview.

[BEGIN RECORDING]

- You can stop participating at any time, and there won't be any consequences.
- There are no right or wrong answers. We just want to hear your honest thoughts and opinions.
- We don't want you to talk about really difficult or upsetting things during this session. If you do feel upset, please tell us, and we can stop the call if you need to.
- If you need to talk to someone for mental health support after this call, you can call the National Crisis line at 988. Claire will paste this number in the chat box for you. [The Nationwide Mental Health Crisis and Suicide Prevention Number can be contacted by dialing 988. This line is available 24/7 if you are feeling distress and want support.]

Orientation to the Project

We want to talk to people who have firsthand experience with substance use disorder or misuse of drugs, including alcohol. We want to know how you decide whether to seek treatment and what kinds of treatment you like. Also, we're curious about what would encourage you to take part in research on different types of treatment.

This research is being done by a group called NEHI, which stands for Network for Excellence in Health Innovation. NEHI is a nonprofit organization based in Boston. They have two partners helping them with this project: Community Catalyst and Black Faces Black Voices. If you want to know more about any of these organizations; website links in the chat for you…

Consent Confirmation

[IF APPLICABLE] We sent you the informed consent form ahead of this call. Did you have a chance to review that?

[IF YES] Do you consent to participating in this study?

[IF NO / WASN'T SENT AHEAD OF CALL – CLAIRE SHARE SCREEN AND TALK THROUGH EACH SECTION BRIEFLY]

Do you feel adequately informed about this study? Do you consent to participating?

Do you have any questions before we begin?

Key Questions

Before we get started, I'd like to talk with you about how we talk about substance use disorder or misuse use of drugs, including alcohol?

- How do you refer to it?
- Is it okay if we use the term substance use disorder?

In this first part, we want to know what made you decide to join this interview today.

- What got you interested in this project? Why did you agree to talk with us today?
- As someone who has experienced substance use disorder or who feels they have misused substances in the past, what do you hope to gain from taking part in this project?

Now we want to understand more about how you make decisions about treatment for substance use disorder or misuse.

- The first time you decided to get treatment, what made you want help? If you haven't sought out treatment before, why?
    - PROBE: How about other times? Were the reasons different? The same?
- Tell us about how you decided what treatments to get.
    - PROBE: For example, therapy, medication, group sessions.
    - PROBE: What sorts of things did you think about when choosing the type of treatment?
- Have you ever tried telehealth for treatment?
    - IF YES: What led you to use telehealth? What did you like about it? Dislike? What were your goals?
    - IF NO: Why?
- What does success look like to you when it comes to treatment or recovery from substance use disorder or misuse?

Many researchers are studying the different ways to treat and support people with substance use disorder. They want to make treatment work better for all people. Sometimes they ask people like you to help with their research, and sometimes they don't. The goal of this project is to find ways to get more people who have been through similar experiences as you to be part of this kind of research. This way, the treatment can be better and match what they really want and need.

To start, we want to know what you think generally about research on treatment for substance use disorder or misuse.

- For starters, tell us what first comes to mind when you think about research and research studies. As a reminder, there are no wrong answers here.
- What do you think about research studies?
    - NOTE: Research studies can be defined broadly – it can mean you answered questions that researchers were looking into by completing a survey or answering a poll or it can refer to clinical research trials, where companies test products with certain populations to see how safe and effective they are for different populations.
    - PROBE: What do you think has shaped your thoughts and opinions on research? For example, do you think a friend's experience, news sources, social media, etc. has shaped how you think about research?
- Have you ever participated in a research study?
    - IF YES: Please tell us about why you participated in that research study.
    - IF NO: Please share why not.
- Scientists and researchers want more people with experience with substance use disorder to get involved in research. What could they do to encourage members of your community to participate? To make research studies more appealing?

    - PROBE: Availability of better information; someone they knew introduced them; adequate compensation; flexibility
- What do you think are some ways that researchers can engage Black individuals who share similar experience as you?
    - If needed use examples such as: How do you get information and where? Who might be a good/safe recruiter for research studies? What information should researchers use when recruiting?

Now we want to know what you think about research that explores the use of telehealth for substance use disorder or misuse.

- What are some issues you wish researchers would look at to help make telehealth services better for Black individuals who have similar experiences as you?
- What do you wish scientists and doctors knew about telehealth for treatment? What kind of information would help you make better decisions about whether and when to use telehealth for treatment?
- If you ever had the opportunity, would you like to give advice to researchers doing a study on telehealth and substance use disorder or misuse treatment?
    - IF YES: Why would this be interesting to you?
    - IF NO: Why not?
- Would you ever consider joining other individuals with similar lived experience in a group created to provide advice to researchers studying telehealth?
    - PROBE: What about this seems interesting or exciting?
    - PROBE: What would you worry about or find difficult?

Appendix E: Written Informed Consent Form

Introduction and Contact Information

Who is running this study?

This study is led by the Network for Excellence in Health Innovation (NEHI), a Boston-based nonprofit group. They are working with Community Catalyst and Black Faces Black Voices. It is funded by the Patient-Centered Outcomes Research Institute (PCORI) (#EACB-30380). The researchers are…If you have any questions, you can contact…at…

Description of the Project

What is the study trying to achieve?

In this part of the study, we will talk to people who have personal experience with substance use disorder or misuse of drugs, including alcohol. We want to know what motivates them to seek treatment and how they choose their treatment options. We also want to find out what would encourage them to take part in research about different types of treatment.

Who can take part in this study?

To join this study, you must be 18 years old or older, identify as Black, live in the Appalachian region, and agree that you have experienced substance use disorder or misuse of drugs (alcohol included). You don't need to be currently seeking treatment or in recovery.

What does participating involve?

The interview will take about 90 minutes. We can do it over the computer (like Zoom) or the phone, whichever you like. Someone on our team will ask you a set of questions related to substance use disorder, treatment, and recovery. Another person will listen in and take notes during the interview. We will record the session just for note-taking purposes. After summarizing the findings from the interview, we will delete the recordings.

What will I get for participating?

As a thank you for taking part in the interview, you will receive a $100 Visa gift card.

Voluntary Participation

Is it up to me to decide if I want to join?

Yes, participating in the interview is entirely your choice, and you can stop whenever you want. If you decide to stop during the interview, please let the facilitator know, but the information you shared before will still be part of the record. You can also choose not to answer any questions. Your decision to participate or not won't have any negative consequences for you. There are no right or wrong answers to the questions we will ask.

Risks or Discomforts

Are there any risks of participating in this study?

The risks of participating in this project are very small. One possible risk is that you might feel upset or uncomfortable during the interview. You may speak with Claire Cruse to discuss any distress or other issues related to study participation. We do not anticipate other significant physical, psychological, legal, or financial risks to you as a participant.

Benefits

What will I gain from participating?

There won't be any direct benefits to you from being part of this study. However, your participation will help us learn more about what treatments and services are essential to people in recovery. This information can guide future research and actions to improve treatment and services and provide better information to the public about the quality of these services.

Confidentiality

Will my information be kept private?

Yes, if you decide to participate, everything you share will be kept confidential. Your answers will remain private, and we won't use your name or any personal details in our reports.

Will this be recorded?

We will record the meetings to help the researchers remember what was said during the discussion. These recordings will be used to create a report about what project participants have shared. But don't worry, your name will never be connected to any of the materials we create. The recordings will be kept confidential on an internal server and used only by the research team. After reviewing them, we will delete the recordings.

If you have any questions, comments, or concerns about the project, please contact [Insert Name…] at [Insert Email].