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Northeast Ohio Opioid Consortium Report

Understanding Experiences of People with Lived Experience Who Use Opioids to Manage Chronic Pain

APRIL
2025

This publication was supported by the Overdose Data To Action LOCAL grant, 1 NH28CE003558, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Introduction

In November 2024, WellLink Health Alliance, formerly The Center for Health Affairs, coordinated a series of focus groups to better understand the experiences of individuals who use opioids to manage chronic pain. These focus groups were supported by the collective work of the OD2A LOCAL (Overdose Data to Action) grant funded through the Centers for Disease Control and Prevention (CDC). WellLink Health Alliance is a subgrantee of this funding through the Cuyahoga County Board of Health. Focus groups were facilitated by Rachael Sommer and Rose McClurkin, Forest City Solutions, Consultant to WellLink for the Northeast Ohio Opioid Consortium.

The purpose of these focus groups was to:

- ✓ Better understand the experiences of individuals living with chronic pain.
- ✓ Use this knowledge to advocate for education, policies, and practices that will improve the quality of care for individuals managing chronic pain.
- ✓ Create responsive educational tools to help patients and providers understand and manage chronic pain.

The findings included in this report are intended to identify next steps and prioritize actions toward the above-identified goals for individuals, clinicians, support systems, and society at large.

Focus Groups Overview

Three 90-minute, virtual focus groups were held throughout November 2024. A total of **12 participants** shared their lived experiences with the facilitation team. When selecting participants for these focus groups, importance was placed on having diverse representation including hospital systems where participants received healthcare, gender, age, geographic distribution, race and chronic pain condition. The participants selected represented the demographic makeup of Northeast Ohio. All of the participants either had previously or currently received care at one or multiple hospital systems in Northeast Ohio.

Feedback received within the focus groups provided insights on a range of topics including experience with chronic pain and managing that pain with opioids, interactions with healthcare providers, experiences of compassionate care, exploration of alternative treatments, barriers to care, and thoughts on stigma and advocacy around opioid use for chronic pain management.

The takeaways shared in the focus groups are explored in more detail below.

Key Insights and Personal Narratives

The themes and findings below are based on questions asked during the focus group. Each section includes narratives from the participants that highlight the insights shared.

Experiences Using Opioids to Manage Chronic Pain

- ✓ Participants across all groups shared that chronic pain significantly impacted their social lives and relationships, financial stability, and emotional well-being.
- ✓ Some emotions that were commonly shared when reflecting on chronic pain were: hopelessness, isolation and frustration.
- ✓ Participants expressed relief from the efficacy of pain relief using opioids and shared that other medications were not as impactful.
- ✓ Participants reflected on trying to balance pain management with the risk of addiction and the social stigma of using opioids.

Participant Reflections

> “Actually, the pains are not something we plan for, so it can happen anytime, anywhere and it just renders someone so almost useless.”
>
> “Opioids were my lifesaver at first, but after a while, it felt like they were controlling me more than I was controlling the pain.”

Stigma and Social Perception

- ✓ The societal stigma around opioid use prevented participants from sharing openly about their experiences with others, leading to further isolation.
- ✓ Participants felt that there is a lack of public understanding that opioids can be used properly and effectively. Instead, participants felt people assumed they were participating in illegal use or suffering from addiction.
- ✓ Participants appreciated alternative treatment options beyond opioids. They felt this information could be more accessible, timely and comprehensive.

Partcipant Reflections

"Society [they] should learn to give us the respect and also learn to treat us fairly."

"I feel like they should acknowledge the complexity and the challenges that makes us currently have this reason of taking opioids."

Barriers to Care

- ✓ Lack of transportation was noted as a barrier to attending appointments.
- ✓ Limited or no insurance coverage resulted in reduced services and an inability to pursue alternative treatments.
- ✓ Participants noted that long wait times between appointments, inaccessible specialists, and unclear medical information led to them feeling ignored by the medical system.

Partcipant Reflections

"So that period where you're waiting can be very difficult. It's usually a time where a lot of things go bad and your pain increases and you're just helpless."

"My insurance does not cover it and because I'm not able to afford all the services I need, I just have to find, you know, a way to deal with my pains. 'cause I'm unable to afford those services and that can be very difficult."

Interactions with Healthcare Providers

- ✓ Positive experiences included providers who actively listened, empathized, and proactively followed up with patients.
- ✓ Participants emphasized the importance of having providers who validate their pain and treat it as a legitimate health issue.
- ✓ Negative experiences involved dismissive attitudes, inconsistent communication, being hard to contact, and assumptions that participants were overreacting to their pain.

Partcipant Reflections

"Sometimes he was the one reaching out to me to know my situation, so he wouldn't probably sit back and expect me to reach out to him. He was making that effort from his own side and I think he's one of the things that will give people sense of belonging"

"They think it's not very serious and we're just making a big deal out of nothing."

Alternative Support and Resources

- ✓ Across all groups, there was interest in exploring non-pharmacological options for pain management including spirituality, yoga, exercise, diet, chiropractic care, physical therapy, group therapy, massages, and others.
- ✓ Success with alternative treatments varied between participants but cost was often a barrier due to lack of insurance coverage.
- ✓ Many participants found these resources through their own research and expressed wishing they would have been recommended by a provider.

Partcipant Reflections

"American Chronic Pain Association online courses helps in advising people about addiction of substances. These educational tools should be recommended."

"I tried mindfulness; it doesn't take the pain away, but it helps me handle it better."

"Yoga was helpful, but after my free trial ended, I couldn't afford to keep going."

Recommendations

The following actionable recommendations originated from participants, their experiences and changes they hoped to see in the future:

Enhance Provider Training

- ✓ Emphasize compassionate care to reduce judgment during patient interactions.
- ✓ Ensure providers clearly explain treatment options and results to enhance patient understanding.

Expand Options and Accessibility to Care

- ✓ Expand healthcare centers, provide transportation assistance, and offer mobile or home-based services.
- ✓ Integrate physical therapy, dietary counseling, and team-based care approaches.

Advocate for Patients

- ✓ Advocate for policies that improve insurance coverage for a range of treatments beyond pharmacological treatments.
- ✓ Encourage policies that support individuals with chronic pain or recovery histories in all places including the workplace.

Peer Support

- ✓ Increase access to in-person and virtual peer support networks.
- ✓ Provide more opportunities for people to share their experiences, educate others and build support networks.

Increase Public Awareness

- ✓ Launch public health campaigns to educate the general public about chronic pain, legitimize opioid use and reduce societal stigma.
- ✓ Create and promote balanced treatment messaging about opioids.

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Conclusion

These focus groups were conducted with diversity in mind to solicit input from people with lived experiences using opioids to manage chronic pain. Questions asked during the session spanned a number of topics including interactions with healthcare providers, stigma, barriers to care, resources and support systems.

These findings are intended for individuals, practitioners, and organizations to understand people with lived experiences better and make changes to increase compassion, reduce stigma, and improve service delivery.

We want to express our deep gratitude to the individuals with lived experience of chronic pain who shared their stories and insights in our focus groups. Your perspectives on managing chronic pain using opioids are invaluable in helping to educate clinicians and treatment programs on how to better serve individuals in need. Your voices are making a difference in shaping more compassionate, informed, and effective care.

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