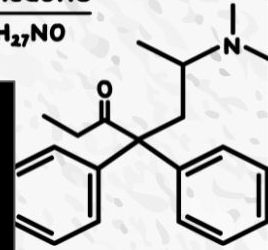


Methodone

$C_{21}H_{27}NO$



Advocating for Persons with Lived & Living Experience: Community Engagement and Empowerment

AMERSA CONFERENCE, 2024

Presenters: Caty Simon, Leslie Suen, Noa Krawczyk, Kate Roberts, Cambria King

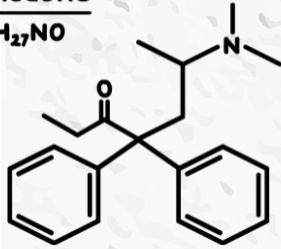
Facilitators: Zoe Weinstein, Paul Joudrey



Learning Goals for Participants:

- Explain how clinicians and allies can support coalitions co-led by and centering People with Lived/Living Experience (PWLLE) to build trust.
- Detail how clinicians and allies can work with PWLLE and call for systemic improvements through a national conference.
- Understand how clinicians and allies can leverage new relationships to generate actionable policy and practice recommendations.





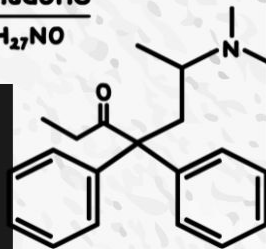
Background

- The details we all know too well:
 - Overdose crisis
 - Worsening effects from the War on Drugs
- The formation of our coalition:
 - Case study of how a group with intersecting identities of People With Lived and Living Experience (PWLLE), addiction medicine clinicians, policy experts, academic researchers, and other allies across the U.S. utilize coalition building to create new partnerships for policy and system change



Methodone

$C_{21}H_{27}NO$



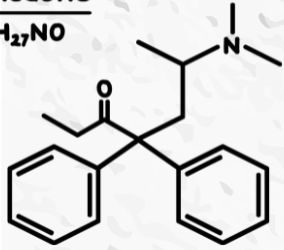


The Creation of The National Coalition to Liberate Methadone

- **Prior to the forming of this group, many precursor activities through National Survivors Union:**
 - **Methadone Mondays x 3 years, SOTA Project, COVID-19 Sign on Letter, National Early COVID Survey On Patient Experiences of Reg Relaxations, and Methadone Manifesto**
- **Perception from National Survivors Union of need to build alliances with providers, researchers, and other groups with allied values**
- **Many people hungry for space to advocate for reform, prevent further harm**
- **Increased use of virtual technology expanded ability to build community**

Simon, C., Vincent, L., Coulter, A., Salazar, Z., Voyles, N., Roberts, L., Frank, D., & Brothers, S. (2022). The Methadone Manifesto: Treatment Experiences and Policy Recommendations From Methadone Patient Activists. *American journal of public health*, 112(S2), S117–S122. <https://doi.org/10.2105/AJPH.2021.3066652>; Nation's Leading Drug Policy Experts Demand Medication Assisted Treatment and COVID-19: Treatment Reforms <https://acrobat.adobe.com/id/urn:aaid:sc:US:3e62be05-acb2-49fb-87d0-24a3424d007e>





The Result:

The National Coalition to Liberate Methadone

- **Uniting a novel community of people who use drugs, people receiving methadone, opioid treatment program clinicians, and researchers by sharing our experiences and discovering common areas of purpose.**
- **We establish common principles seeking to reduce overdose harms and create a culture of embraced discussion of controversy and differences.**
- **These new relationships were not transactional and highlighted the need to center the voices of directly impacted individuals in research and policy.**





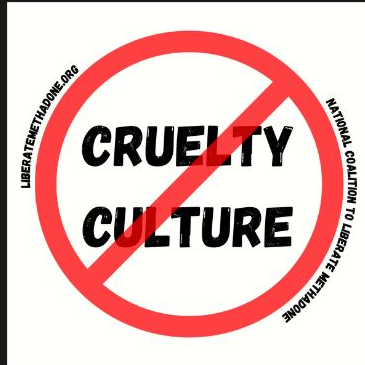
NCLM Mission Statement

Methadone saves lives, but outdated and punitive methadone policies cause harm. As the overdose crisis continues to ravage our families and communities, it is time for a change. The National Coalition to Liberate Methadone advocates for a more accessible and equitable methadone system that prioritizes patient health, promotes dignity, and is grounded in evidence.

Founded in 2022, the National Coalition to Liberate Methadone is a national organization made up of over a hundred people, including people with lived or living experience on methadone, advocates, addiction medicine clinicians, and substance use researchers across several U.S. states. NCLM members are active participants, providers, evaluators, and clinical leaders of OTP clinics across the country, giving them deep expertise and commitment to improving the health of people on methadone. NCLM supports efforts to expand methadone treatment access for all individuals with opioid use disorder, as methadone has decades of evidence supporting its efficacy in reducing morbidity/mortality, and improving quality of life and treatment retention.



Advocacy Activities & Working Groups



- **Federal**
- **State**
- **Capacity building**
- **Dissemination of
conference proceedings**
- **Daily clinical care**



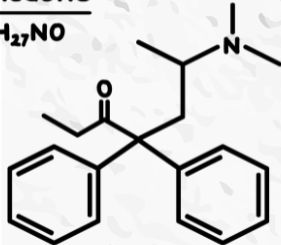


Break Out Session #1: Partnership (12 minutes discussion)

Introduce yourself to others at your table & discuss the following questions:

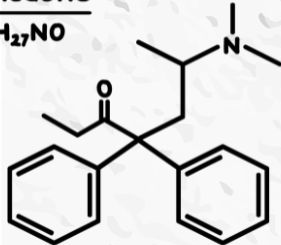
- If you work in a healthcare space (whether as a clinician, researcher, peer, etc.), how would you go about building connections with PWLLE?
- If you are PWLLE, how would you go about building networking ties with those working in healthcare spaces?
- Discuss any previous experience you may have had doing so and utilize the example of the formation of the National Coalition to Liberate Methadone to think about how you might initiate these connections in your area.
- Pick a speaker for your table for report back.





Advocacy Amplified: Calling for Systemic Improvements through a National Conference





The Inaugural Liberating Methadone Conference



The Inaugural Liberating Methadone Conference

Members of NCLM came together to form a conference planning committee.



Partnered with NSU and Academic Partner (NYU School of Medicine) through NCLM member affiliations to increase reach, manage conference funding & logistics



Conference Objectives

- **Aim 1:** Create a roadmap for a more accessible and equitable OUD treatment system that delivers methadone via a non-specialty care/pharmacy system.
- **Aim 2:** Identify new research avenues and strategies to conduct community-engaged research that can guide the development of a more accessible and equitable system.
- **Aim 3:** Draft recommendations for a path forward that can guide the policy and practice reforms necessary to establish a non-OTP centered methadone treatment system.

Overarching guiding principle for conference: Center the voices of people with lived and living experience on methadone



Applying for and working with funders

The NYU Langone Department of Population Health, Division of Epidemiology & Center for Opioid Epidemiology and Policy (COEP)

The Pew Charitable Trusts

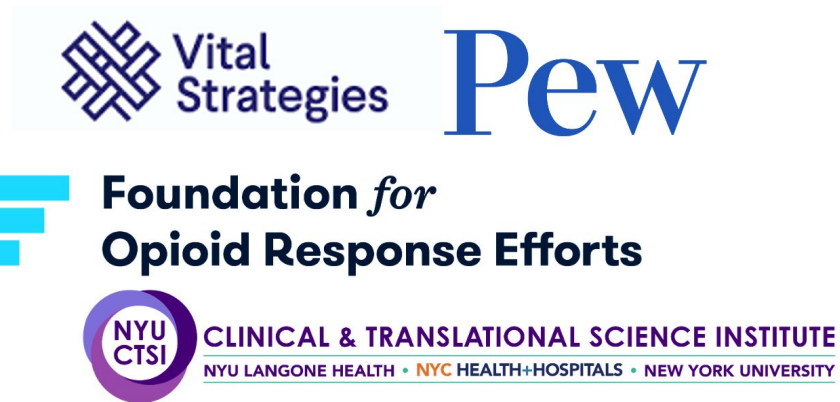
Vital Strategies

Bloomberg Philanthropies

Foundation for Opioid Response Efforts (FORE)

NIH/National Institute of Drug Abuse (NIDA) *R13 DA058520*

NYU-H+H Clinical and Translational Science Institute (CTSI), which is supported by the National Center for Advancing Translational Sciences (NCATS) *UL1TR001445*.





Conference dissemination and publicity

Drug user union and methadone advocacy networks

Academic societies and organizations

Social media outlets



National Coalition to Liberate Methadone @MethadoneLi · May 11, 2023 ...
Methadone Conference!!!
Save the date - Sept. 21 & 22nd

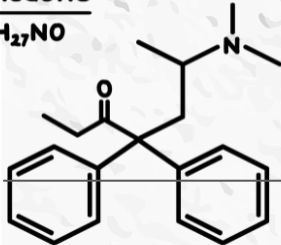
Collaborate with others interested in liberating **methadone!** (Online and In-person)

Liberating **Methadone**: Building a Roadmap and Community for Change

The poster features logos for Pew, NYU Langone Health, and NIH (National Institute on Drug Abuse) at the top. The main text is on a purple background: "Sept. 21 & 22, 2023" and "Liberating Methadone: Building a Roadmap and Community for Change". Below this, it says "Abstract submissions, scholarships, and registration to follow!". The location is "Kimmel Center, 60 Washington Square South, New York, NY 10012". A hybrid icon and the text "This conference is HYBRID!!!" are also present. Logos for NYU and Vital Strategies are at the bottom.

A social media post from Aaron Ferguson (@sciencenotheism) dated 8/29/23. The post includes a profile picture and a video thumbnail showing a red pill bottle behind black prison bars. The text of the post says "Listen to 'The Miracle in the Molecule' by Naturally Noncompliant." At the bottom, it lists "podcasters.spotify.com" and "The Miracle in the Molecule by Naturally Noncompliant".





Conference Accessibility & Affordability

- Travel awards (31) for people with lived and living experience
- No fee registration
- Virtual conference attendance option
- Child care information
- Guest dosing for those on methadone
- Naloxone, fentanyl/xylazine test strips distributed on site





Success at Recruiting Diverse Group!

- **800+** people registered

- 49.5% in person

- 50.5% remotely

- **A wide diversity of life experiences:**

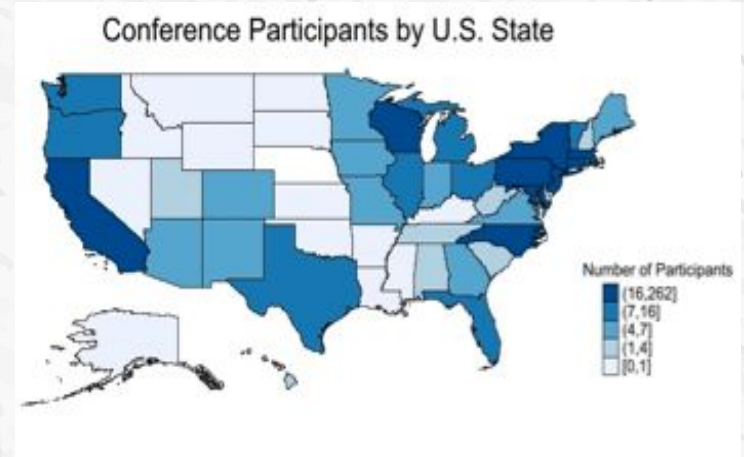
- **44** U.S. states and **10** countries

- **11%** live in a rural community

- **33%** identify as being a member of a minoritized group

- **34%** identify as having lived or living experience with substance use or substance use disorder

- **16%** identify as having lived or living experience with methadone treatment



Other Countries and Territories

Puerto Rico

Belgium

Canada

India

Iran

Japan

Mexico

Taiwan

United Kingdom



Conference Agenda Highlights

Panel Discussions:

Panel 1: Gaps and Opportunities in Methadone Research

Panel 2: Conducting Community-Engaged Research on Substance Use

Panel 3: How did we get here?

Panel 4: Where are we now?

Panel 5: A chance for change: where could we go?

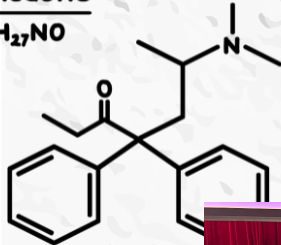




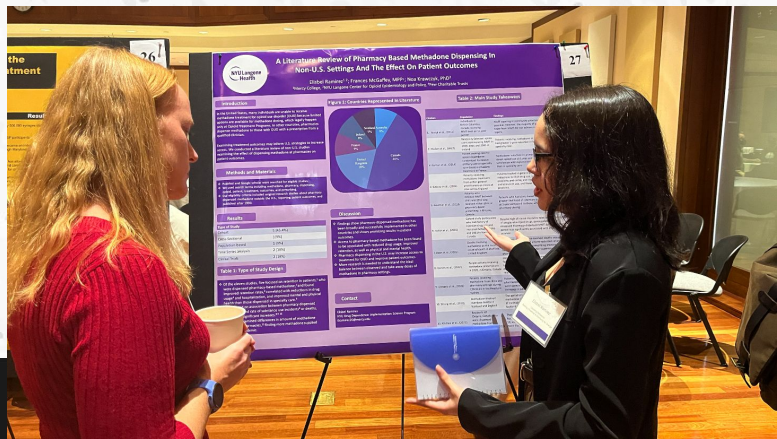
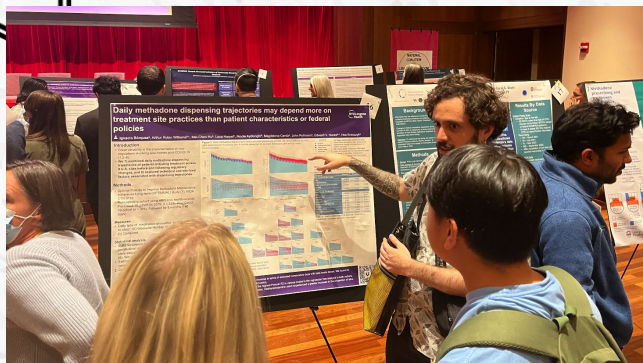
Skill building workshops

1. Becoming an effective drug policy reform advocate: bridging the research-policy divide
2. Extreme makeover methadone edition: innovative strategies for integrating methadone and essential health services
3. Demystifying office-based methadone: lessons from international models
4. Surviving the opioid treatment program system
5. From baby steps to giant leaps - advancing the transformation of methadone law and policy





Poster Session



NEW YORK UNIVERSITY

WHY ILLICITLY SOURCED DIVERTED METHADONE IS A SAFER CHOICE FOR ME

Have you ever been a patient in an opioid treatment program/methadone clinic?

YES

Have you ever experienced sexual harassment/assault perpetrated by clinic staff or other patients?

YES

WE'RE TAKING YOUR TAKE-HOMES THROUGH YOUR URINE WAS NON-REACTIVE!

I'm sorry you've experienced that.

Have you ever been denied trauma informed care at a methadone clinic?

YES

Unfortunately that is quite common.

Have you ever experienced harassment by clinic staff on the basis of your chosen occupation?

YES

IF MY COUNSELOR TELLS ME AGAIN THAT MY HUSBAND DOESN'T LOVE ME BECAUSE I'M A SEX WORKER I'M GOING TO SCREAM!

Have clinic staff ever threatened to withhold your dose based on how you were dressed?

YES

YOUR CLOTHING IS DISTRACTING THE MALE PATIENTS!

Congrats! You probably identify as a marginalized gender and may participate in an alternative economy. These intersecting identities can make navigating the OTP system more difficult or even dangerous. Diverted supply may be a safer choice for you as well.

NO

Please stay in your lane and respect the lived experiences of survivors.

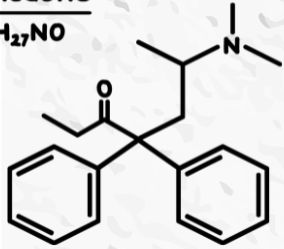
Congrats! You probably do not belong to a marginalized gender.

Please stay in your lane and respect the lived experiences of survivors.

Congrats! You probably do not belong to a marginalized gender or support yourself with alternative economies.

Congrats! You probably do not belong to a marginalized gender or support yourself with alternative economies.





Post-conference awareness rally



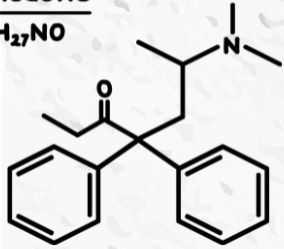


Concerted efforts to engage multiple audiences in discussion

We want to hear from you!

All proceedings from conference will be
used to inform a report with
recommendations for policy and practice





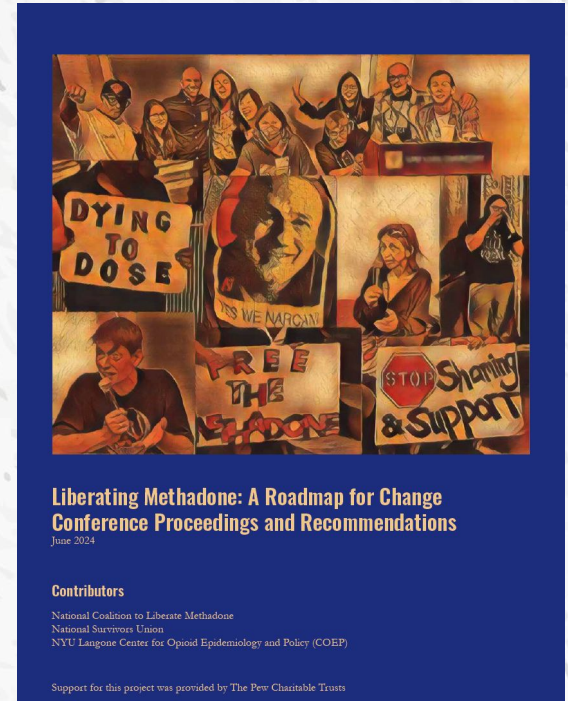
Generating Actionable Policy and Practice Recommendations

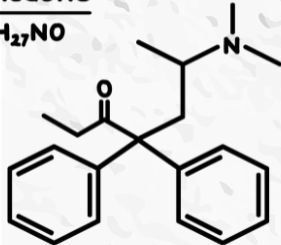
After the conference, brought together post-conference working groups tasked with reviewing preliminary proceedings from conference

- Participation in two facilitated virtual meetings, to generate:
 - Recommendations for practice
 - Recommendations for policy



Download and read report here!





Summary of Recommendations by Focus Area

1. Centering Living and Lived Experience in Policy and Practice
2. Normalizing Methadone Treatment as Healthcare
3. Grounding Methadone Treatment in Person-Centeredness
4. Improving OTP Practices
5. Creating Alternatives to the OTP System
6. Shifting Public Thinking about Methadone



Download and read report here!



Break Out Session #2: Advocacy (12 minutes discussion)



How might you implement advocacy efforts in coalitions between PWLLE, clinicians, researchers, and other allies in your area?

Choose a topic you may be interested in advocating for around substance use clinical practice. Brainstorm:

What groups might you want to bring to the table?

What sources of funding could you use to support these efforts?

How can you ensure these efforts result in actionable proceedings or next steps?

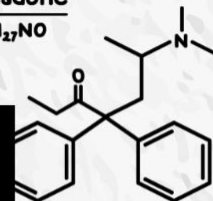
Choose a speaker to represent your table.





Follow. Contact. Join.

Methadone
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@MethadoneLib



methadoneadvocacy@googlegroups.com

#METHADONEREFORM

#ENDTHECULTUREOF CRUELTY