Top Priorities Identified So Far

Survey
- 800+ responses to a national online survey identified the top 3 outcomes people with substance use challenges and people in recovery want for themselves in “typical” (non-COVID-19) times. There are differences in top three outcomes by gender and race.
- During the COVID-19 pandemic, the third priority changed. Feeling safe in their surroundings also became an imperative.

Focus Groups
- 10 focus group participants identified different desired outcomes from survey respondents.
- Focus group participants maintained these top priorities during COVID-19 while adding other priorities.

"Typical" Non-COVID-19 Times

1. STAY ALIVE
2. HAVE IMPROVED QUALITY OF LIFE
3. STOP ALL DRUG / ALCOHOL USE

COVID-19 Pandemic

1. STAY ALIVE
2. HAVE IMPROVED QUALITY OF LIFE
3. IMPROVE MENTAL HEALTH

Patients Lead: Identifying Meaningful Outcomes to Drive Substance Use Disorders Research and Care – Preliminary Findings December 2020

Community Catalyst is partnering with Faces & Voices of Recovery and the American Society of Addiction Medicine to increase the voices of people with substance use challenges and people in recovery in influencing research and improving treatment outcomes through “Patients Lead.”

People were eligible to participate in the survey or focus group if they were at least 21 years old and had lived experience with substance use challenges, including addiction.
The Takeaway

Several of these desired outcomes are not commonly the focus of research or clinical practice to address substance use disorders. Typically, that research has focused more on whether a patient received any treatment, and whether they stopped all substance use. In addition, desired outcomes vary by race and gender. Based on this initial analysis, the Patients Lead project team recommends:

**Providers**
- Clarify each individual’s desired treatment and recovery goals
- Adjust services to meet those goals, recognizing these goals may vary by race, gender and other demographics
- Integrate mental health supports into substance use disorders services

**Policymakers**
- Make permanent the temporary policies enabling expansion and payment for virtual services, including take-home medication doses and phone counseling
- Dedicate funding to support virtual services and integrated mental health and substance use services, particularly in communities of color and in rural areas
- Increase funding for peer services, recovery community organizations and other recovery supports that connect people to community services
- Ensure policy changes address the needs of people marginalized due to race, ethnicity, gender or other identities

**Researchers**
- Prioritize research on what treatments and services are most effective in helping patients achieve the results they prioritize—for example, investigate what treatment approaches most increase quality of life
- Research the best ways to expand access to virtual services
- Explore differences across race, ethnicity, gender and other identities

Why This Matters

People with lived experiences of substance use disorders are often left out of important policy decisions that affect their lives, including how treatment and recovery programs are designed and what outcomes those programs seek to achieve. This means that services aren’t always responsive to people’s needs and don’t always achieve the best outcomes. We aim to change this by identifying what outcomes of treatment and services matter most to people and ensuring their voices guide future research and treatment.

Read the full preliminary findings here!

This report is funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (12786-CC)