Developing a Cascade of Care Framework and Surveillance Indicators to Measure Linkage to and Retention in Care for Substance Use Disorder

Emily N. Ussery, PhD, MPH
Epidemiologist, Division of Overdose Prevention

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Overview

+ Background
+ Indicator Development Process
+ Cascade of Care for Substance Use Disorder
+ Linkage to and Retention in Care Surveillance Indicators
+ Next Steps
+ Discussion
Background
Background

• Ensuring persons with substance use disorders (SUD) are linked to evidence-based treatment is critical for overdose prevention

• Range of settings or entry points where persons with SUDs can be identified and connected to care and treatment (“no wrong door”)
  • Emergency departments, hospitals, outpatient clinics, primary care
  • Jails, prisons, correctional facilities, drug courts
  • Harm reduction programs/syringe services programs
  • Community-based organizations
Background

• Limited availability of standardized surveillance data to understand linkage to and retention in care for substance use disorder

• Expanding surveillance of linkage to and retention in care will complement prevention-focused activities and support public health agencies’ efforts to evaluate linkage to care programs

• **Goal:** Develop resources and guidance for health departments to:
  - Improve and standardize surveillance of linkage to and retention in care
  - Collect data to inform linkage to care prevention activities
Overdose Data to Action (OD2A)

• Current funding provided to 66 state, local, and territorial health departments to expand and strengthen overdose surveillance and prevention efforts

• Recipients are required to implement at least one Innovative Surveillance project that aligns with several priority areas, including linkage to care surveillance
  • Did not require standard indicators or protocols
  • Aggregate data products shared with CDC annually

• Approximately 20 recipients proposed innovative surveillance projects with a linkage to care component
Indicator Development
Indicator Development Process

• Previous contract with Kahuina Consulting, LLC

• Tasks:
  1. Identify a feasible set of standardized surveillance indicators to monitor linkage to and retention in care
  2. Develop guidance for health departments to implement the indicators

• DOP staff met biweekly with Kahuina project team

• Provided relevant background materials from OD2A recipients
  • Jurisdictions working on linkage to care surveillance projects
  • Relevant innovative surveillance data products
Indicator Development Process

- Review of peer-reviewed studies and government reports
- Review of OD2A Innovative Surveillance data products
- Discussions with OD2A recipients
Indicator Development Process

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- Discussions with OD2A recipients
- Compiled findings into an environmental scan
- Defined Cascade of Care for SUD and identified broad list of indicators
Indicator Development Process

- Review of peer-reviewed studies and government reports
- Review of OD2A Innovative Surveillance data products
- Discussions with OD2A recipients
- Compiled findings into an environmental scan
- Defined Cascade of Care for SUD and identified broad list of indicators
- Refined list of indicators
- Developed toolkit
Cascade of Care for Substance Use Disorder and Associated Indicators
Linkage to and Retention in Care Surveillance Indicators

A. Individuals with Potential Substance Use Disorder (SUD) Identified, by Entry Point

**Description**
The number of persons with potential SUD identified at each entry point to care.

**Example Measure**
Number of persons treated for a nonfatal overdose in the emergency department.

**Entry Points:**
- Treated for nonfatal overdose in emergency department or by EMS
- Diagnosed with or treated for a substance-use related condition in a clinical setting (non-overdose)
- Criminal-justice involved (e.g., released from incarceration)
- Harm reduction programs (e.g., syringe services program [SSP])
- Other community-based programs
- Self-referrals
## Linkage to and Retention in Care Surveillance Indicators

### Example Measures

#### A. Individuals with Potential Substance Use Disorder (SUD) Identified, by Entry Point
- **Description**: The number of persons with potential SUD identified at each entry point to care.
- **Example Measure**: Number of persons treated for a nonfatal overdose in the emergency department.

#### B. Individuals Engaged through Linkage to Care (LTC) Programs
- **Description**: Among those identified, the number of persons who engage with LTC program staff.
- **Example Measure**: Percent of persons treated for a nonfatal overdose who are engaged by LTC program navigators/linkage coordinators.

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# Engaged
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### Linkage to and Retention in Care Surveillance Indicators

#### Service Type

1. Medications for opioid use disorder (MOUD)
2. Behavioral treatment (e.g., cognitive behavioral therapy, motivational interviewing, contingency management, other counseling support)
3. Harm reduction services (e.g., SSPs, overdose education and naloxone distribution)

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Key Characteristics

• Sociodemographic characteristics
  • Race/ethnicity
  • Sex
  • Age category
  • Homelessness
  • Sexual orientation
  • Gender identity

• Substance type
  • Opioids
  • Stimulants
Implementation Challenges and Considerations

• Varying levels of capacity within local and state health departments

• Indicator measurement relies on data from multiple sources and agencies
  • Availability of and access to data sources varies across jurisdictions

• Linking data on “identification” (e.g., nonfatal overdose, SUD diagnosis) with treatment received is difficult
  • 42 CFR Part 2 and state regulations limit access to treatment data, especially identifiable data
  • Population can be difficult to follow-up with

• Movement through the cascade of care is not always linear
  • Individuals may enter at multiple entry points and/or time periods
  • Individuals may be lost to follow up and re-engage in care
Next Steps

**Indicator Development: New Kahuina Contract**

- Interactive workshops with current OD2A recipients
- Continue to refine indicators and finalize toolkit
- Publish commentary to describe indicator development process

**OD2A: LOCAL**

- Fund local health departments to establish a linkage to and retention in care surveillance system
Overdose Data to Action: Limiting Overdose through Collaborative Actions in Localities (OD2A: LOCAL)

+ Notice of Funding Opportunity announced on 3/7/2023

+ 5-year cooperative agreement (begins Sept 2023)

+ City, county, and territorial health departments are eligible to apply

+ Funding for prevention and surveillance activities

+ Component C: Linkage to and Retention in Care Surveillance
Key Requirements for Component C

1. By September 2024, begin collecting data to measure standardized linkage to and retention in care surveillance indicators

2. Beginning in December 2024, submit aggregate data to CDC every 6 months

3. Analyze and disseminate linkage to and retention in care surveillance data to inform prevention efforts

4. Designate at least one representative to participate in CDC workgroup meetings
Requirement #1: Collect standardized indicators

• 12-month planning period (Sept 2023 – Aug 2024)

• Required to focus data collection on populations identified via at least 2 priority entry points to care:
  • Treated for a nonfatal overdose (REQUIRED)
  • Diagnosed with or treated for a substance-use related condition in a clinical setting
  • Criminal-justice involved
  • Harm reduction programs
  • Other community-based programs
  • Self-referrals
Requirement #1: Collect standardized indicators

- Standardized indicators will assess stages across a cascade of care for SUD, which include:
  1. Persons identified as at-risk via priority entry points
  2. Persons engaged with linkage to care program staff
  3. Persons referred to evidence-based treatment (e.g., MOUD, behavioral health treatment) and other support services (e.g., harm reduction services)
  4. Persons linked to care/initiated treatment
  5. Treatment status 6 months after initiation (MOUD and behavioral health treatment only)

- Indicators may be stratified by key characteristics, such as substance type, age, sex, race, ethnicity, and county of residence

- Encouraged to collect individual-level data that can be linked across indicators
Requirement #2: Submit aggregate data to CDC

- First required data submission will be in December 2024
- Required to submit aggregate data to CDC every 6 months
- CDC will provide detailed data submission guidance, a data submission timeline, and templates that must be used to submit data
- CDC will work closely with recipients to ensure any publicly reported data meets minimum data quality standards
Requirement #3: Disseminate data to partners

- Required to disseminate data products using linkage to and retention in care surveillance data to key local partners and/or the public
  - At least one data product per year
  - Beginning in Year 2
- This may include web pages, reports, presentations, or peer-reviewed manuscripts
- Submit an annual bibliography of relevant data products to CDC
 Requirement #4: Participate in workgroup

• Designate at least one representative to participate in required CDC workgroup meetings
• Workgroup meetings will be held on at least a quarterly basis
• Discuss issues related to data collection and data dissemination
• Identify additional indicators for reporting in later years
• Collaborate on updating guidance and data submission requirements
Thank you!

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
Discussion Topics

+ Do you have any feedback on the proposed indicators?
Discussion Topics

Do you have advice on how we might develop or adapt guidance to accommodate varying levels of surveillance capacity within health departments, and ultimately support their data collection?
Discussion Topics

+ Do you have suggested areas of focus for the interactive workshops with state and local health departments?
  - Scenarios or entry points
  - Specific indicators
  - Implementation considerations
Discussion Topics

Do you have suggestions for stratifying indicators by substance type?
- Opioid use disorder (OUD)
- Stimulant use disorder (StUD)
- Co-occurring OUD and StUD
Questions?