



## **Overdose Data to Action (OD2A): Innovative Surveillance Community of Practice**

*Key Findings from the Linkage to Care (LTC) Workgroup*

In 2019, the CDC National Center for Injury Prevention and Control (NCIPC) expanded support for overdose surveillance and prevention activities by launching the [Overdose Data to Action \(OD2A\)](#) cooperative agreement. Funds awarded as part of this agreement support state, territorial, county and city health departments in obtaining more comprehensive and timelier data on overdose morbidity, implementing innovative surveillance projects and using these data to inform prevention and response efforts.

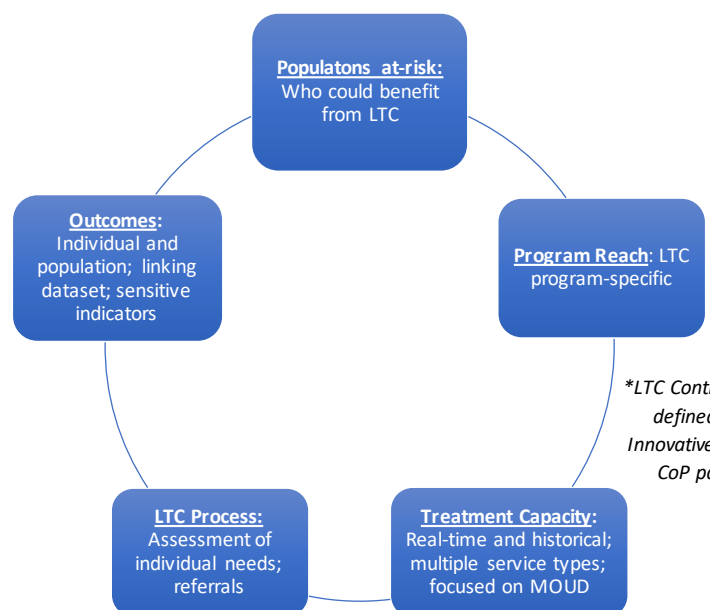
In partnership with the CDC, the Council of State and Territorial Epidemiologists (CSTE) established the Innovative Surveillance Community of Practice (CoP) to support jurisdictions implementing innovative surveillance strategies. The CoP consists of three distinct workgroups: 1) Linkage to Care (LTC) Surveillance; 2) Local Outbreak Detection (LOD); and 3) Monitoring Illicit Drug Supply (MIDS). This executive summary contains key findings specifically related to the LTC workgroup.

The authors participated in all CoP workgroup meetings held between January and June of 2021, facilitated discussions with workgroup members, reviewed materials that pertain to workgroup meetings held during the second half of 2020, and conducted interviews with eight jurisdictions to gather additional information about approaches and methods used to conduct surveillance of their LTC activities. Key findings from the LTC surveillance workgroup include the following:

- The purpose of LTC surveillance is to track persons along the continuum of care and whether they were referred to and initiated treatment. It also allows opportunities to evaluate LTC prevention activities, measure the population that LTC programs are reaching, and the impact on that population. Interviews suggest that LTC surveillance approaches are highly customized to the target population, which vary but can be categorized as: a) LTC initiated by clinical events; b) LTC initiated by law enforcement or correctional systems; c) self-initiated LTC; and d) LTC initiated through community organizations and harm reduction services.
- Workgroup participants and interviewees described the limited ability to modify traditional public health surveillance systems for LTC surveillance needs. Most workgroup participants and interviewees built their own systems to collect LTC process data using software and systems such as Excel, Qualtrics, REDCap and Google sheets.

- There was no standard Linkage to Care definition that was used when LTC projects began. The different linkage to care surveillance projects focused or discussed tracking data on: 1) assessment of individual needs, 2) making referrals, 3) confirming the referred individual initiates treatment, and 4) confirming the referred individual completes treatment. Though surveillance of all four steps is important, interviews and workgroup discussions focused almost exclusively on assessment of individual needs and making referrals to treatment services.
- LTC surveillance can be described as a continuum of care<sup>i</sup>, which mirrors the HIV continuum of care (I.e., care cascade).<sup>ii</sup> In lieu of recommended linkage to care indicators, jurisdiction projects cut across the following domains: population at risk, program reach, treatment capacity, linkage process and outcomes.
- Three of eight interviewees had statewide information systems from crisis lines or referral platforms and these organizations had greater functionality to track detailed linkage process data. These interviewees have timely access to process data, and some can extract data directly from the system at the individual level.
- LTC workgroup participants and interviewees noted a number of challenges related to surveillance of LTC activities, including the following:
  - a) Gaps in surveillance of populations at risk and program reach including inability to estimate the number of people injecting drugs or how many people are receiving care for opioid use disorder
  - b) Gaps in treatment capacity surveillance including limited access to real-time treatment data and no visibility or information in the private treatment landscape, which is a large proportion of treatment resources
  - c) Tracking LTC outcomes including limited systems, resources, and jurisdictional bandwidth to track LTC outcomes
  - d) Sensitivity of data on patients with substance use disorders including opioids (e.g., concerns about sharing data covered by [42 CFR Part 2](#)) including hesitancy from partner organizations to share data with public health in addition to laborious data use agreements to obtain access to LTC data
  - e) Accessing and analyzing data from prescription drug monitoring programs (PDMPs) including highly restricted data access, costs associated with data-requests, as well as limited ability of workgroup members to access or request PDMP data within their jurisdiction

#### Linkage to Care Continuum of Care \*



*\*LTC Continuum of Care defined by OD2A Innovative Surveillance CoP participants*

- f) Shortage of treatment capacity causes a challenge to conduct successful surveillance because individuals cannot proceed through the intended LTC process
  - g) Fragmented treatment landscape: Jurisdictions often use a variety of manual processes to request, extract and integrate data from each source together due to fragmented services across multiple types of organizations
  - h) Poor data quality: Most health departments exchange deidentified data, which limits capacity to identify, characterize, and reconcile data quality issues in addition to face challenges obtaining complete and accurate data from hospitals.
  - i) Lack of timely data: LTC programs desire real-time data about treatment as well as real-time access to outcomes that could help LTC programs follow up and re-link individuals back into care.
- A number of opportunities were also identified by LTC workgroup participants to strengthen LTC surveillance activities, including the following:
    - a) Clarify distinction between LTC prevention activities versus LTC surveillance: The lack of distinction between LTC activities and LTC surveillance suggests that these activities are interrelated from a programmatic perspective but represents an opportunity for additional guidance and clarity.
    - b) Deepen knowledge about how induction and MOUD treatment is delivered: Cultivating a greater understanding of how organizations provide MOUD treatment could improve LTC program staff capacity to tailor linkage processes to treatment organization's needs
    - c) Support transition from smaller, pilot LTC program to larger, sustainable program including the need for programs to have a more robust approach to surveillance and tracking that prioritizes capturing detailed individual level data through secure information systems and stores data in a format to be linked to additional data sources.
    - d) Document data and indicator definitions: Jurisdictions reported collaborating internally with public health as well as with community stakeholders to develop data and indicator definitions.
    - e) Convene opioid partners to share data frequently including using data sharing to promote a culture of trust and transparency as well as convening a diverse group of partners to share surveillance data across the LTC continuum
    - f) Align data systems with LTC program and/or clinical workflow including identifying a need for LTC surveillance systems that reflect specific LTC program structure and workflow
    - g) Align LTC program with logic model including mapping LTC activities to short-, medium- and long-term outcomes to guide the LTC programming and surveillance work
    - h) Develop and use dashboards to share data with LTC partners including public dashboards that can be shared with LTC partners, healthcare providers, and the interested public

Based on information gathered from all CoP workgroup discussions, presentations, and interviews, CSTE identified recommendations for additional guidance and technical assistance to OD2A recipients on building capacity for data governance to facilitate data sharing, overcoming challenges to working with prescription drug monitoring programs (PDMPs), and continuing to support collaborative learning across OD2A-funded jurisdictions. The insights gained from the conversations with subject matter experts and proposed recommendations will be used by CSTE to inform efforts to support public health jurisdictions implementing innovative surveillance strategies related to linkage to care surveillance.

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<sup>i</sup> Socias ME, Volkow N, Wood E. Adopting the 'cascade of care' framework: an opportunity to close the implementation gap in addiction care? *Addiction*. 2016 Dec; 111(12):2079-2081.

<sup>ii</sup> HIV Continuum of Care. <https://www.cdc.gov/hiv/policies/continuum.html>