2024 MASSACHUSETTS OVERDOSE PREVENTION RESEARCH SUMMIT HIGHLIGHTS & NEXT STEPS

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Outlook on the Day:

A motivating set of questions posed to the group at the day's outset was: "At the end of the day, we want to improve the health of the community, and all the elements of what it means to be healthy with your relationship with drugs and alcohol. What is our strategy? What are our priorities? What is the equity outlook on this?"

The Summit brought together over 50 researchers and DPH employees to discuss progress in overdose research in Massachusetts and next steps for the state. The day began outlining various data sources maintained by the Massachusetts Department of Public Health (DPH) to analyze drug overdoses and the health of individuals using drugs. Notable data limitations across the sources related to timeliness, level of detail, and flexibility and responsiveness. There are opportunities for utilization, and researchers can access the data, but the process is opaque and may be time and resource intensive. The creation of public dashboards was an exciting new chapter in data sharing, and optimizing their content, uptake, and interactivity via user experience and design inquiry is a place of future growth for DPH. Workgroups met later in the day to dive more deeply into these ideas.

Summit attendees also exchanged in a moderated discussion highlighting key lessons learned from Massachusetts research on overdose, emphasizing the importance of collaboration with individuals who use drugs and the need for equitable resource allocation. Key takeaways include:

1. **Partnership and Equity**: Engaging with the drug-using community is crucial for effective interventions, and equity demands dedicated resources.
2. **Diverse Drug Use**: Understanding various drug consumption methods (beyond injection) is necessary, particularly as overdose patterns evolve, especially with fentanyl.
3. **Naloxone Limitations**: While naloxone distribution is vital, it alone cannot address the rising overdose death rates. There's a need for comprehensive data collection and analysis.
4. **Understanding Trends**: Non-fatal overdoses and the impact of COVID-19 on emergency calls should be better understood through syndromic surveillance.
5. **Collaboration Across Sectors**: Working with law enforcement and pharmacies can enhance care access, and there's a need to explore geographic and logistical barriers to treatment.
6. **Research Needs**: Mixed methods research is essential to fill data gaps, with an emphasis on qualitative insights and effective dissemination of findings.

Looking forward, research priorities discussed and "dot voted" by the group include:

- **Identifying At-Risk Populations**: Understanding the demographics of those affected by overdose is critical for targeted interventions.
- **Addressing Unwitnessed Overdoses**: Developing programs to mitigate this issue is essential.
- **Improving Treatment Accessibility**: Making treatment more patient-centered and expanding access through diverse venues like telehealth and pharmacies is vital.
- **Youth Engagement**: Focusing on younger populations and community involvement in treatment approaches is necessary.
- **Supporting the Workforce**: Understanding and addressing the needs of those in the treatment workforce, including policy changes, is crucial for effective support.

Overall, the discussion emphasized a holistic, inclusive, and data-informed approach to addressing overdose and improving health outcomes for individuals who use drugs.

Community Engaged Research and Shaping ECKS-O to Future Needs

A session on Community Engaged Research focused on insights from the RACK initiative, which aimed to inform policy and services related to harm reduction in Massachusetts. In shifting to new data collection approaches, the ECKS-O overview explained how this new initiative is modeled after similar programs nationwide, incorporating community feedback, researcher involvement, and appropriate compensation. It aims to gather comprehensive data on overdose, drug use, naloxone needs, and treatment options as a complement to existing administrative databases. Methods include surveys, interviews, ethnographic observations, and photovoice, while addressing concerns about survey quality, literacy, and accessibility for people who use drugs (PWUD). Community researchers (i.e., hiring and training PWUD to collect data) would be a central feature of this approach.

A review of best practices in Community Engagement underscored that effective engagement involves treating community members as research partners, hiring individuals with lived experience, embedding research in communities, ensuring mutual benefits, and sharing findings in accessible formats.

Some of the barriers identified and shared by researchers, though, served as a reminder of the need for refinement of data collection for community engaged research to succeed. A survey of harm reduction organizations highlighted several barriers to annual data collection if it were to take a community researcher-focused approach, including limited staffing, lack of private spaces for surveys, time constraints, and the need for management buy-in. Additionally, Respondent Driven Sampling (RDS) was deemed infeasible due to its pressures and potential inequities.

Proposed Solutions: To address these barriers and concerns, the discussion suggested shifting from RDS to utilizing existing datasets from the Public Health Data Warehouse (PHD) and other state programs to create a stratified random sample of at-risk individuals. This approach was further explored in ongoing discussions among summit participants, about which the ECKS-O team is following up. Additionally, it was recommended that the study team expand the number and type of programs and individuals included in studies to prevent participant burnout and explore new areas of interest.

Afternoon Workgroups

There were three working groups, where facilitators led discussions with group attendees about important aspects of their theme. Each workgroup looked at current data use and limitations and then examined gaps in overdose prevention research where future research is needed.

#1 Administrative Data Workgroup

Question 1: What are the most and least used quantitative or admin data sets used to research and evaluate activities related to overdose in MA? What are the limitations of the data sets being used?

- **Access to Data**: MassHealth and the Center for Health Information and Analysis (CHIA) are key resources, but CHIA tends to prioritize government requests over research. MassHealth is more flexible but requires agreement for sensitive claims data.
- **Underutilization of CHIA**: Many find CHIA data difficult to access and navigate, despite its value. Claims related to substance use are protected under 42 CFR Part 2, impacting research accessibility.
- **Data Coverage**: The data primarily reflects those who have had insurance, leading to gaps for uninsured individuals and those incarcerated. Incarceration data is not captured in the Public Health Data Warehouse (PHD).

- **Limitations of Claims Data**: The data serves as billing records rather than comprehensive health service records, complicating trend analysis, especially during transitions in coding systems (e.g., ICD-9 to ICD-10).

Question 2: What are the gaps in overdose prevention research in MA and how can DPH help address those gaps in large data sets?

- **Infectious Disease**: There's a need for research on how infectious diseases (like TB) intersect with substance use, which could lead to public health crises.
- **New Protocols for EMS**: Although a new protocol allows EMS to administer buprenorphine after naloxone, no agencies have adopted it. Identifying barriers to implementation is crucial.
- **Data Collection Challenges**: Gaps exist in data for those refusing services. Free text fields in reports complicate data processing due to privacy concerns.
- **Variation in Care**: Understanding variations in care requires including facility codes in datasets.
- **Policy Advocacy**: There's a need for data to support policy changes, such as reforms related to Section 35 and non-punitive care approaches.
- **Missing Touchpoints**: Important data points are lacking from agencies like the Department of Children and Families (DCF), and regarding criminal involvement, housing status, and treatment discontinuation.
- **Outcome Evaluation**: BSAS needs better mechanisms to evaluate the effectiveness of resources aimed at improving access to treatment for medication for opioid use disorder (MOUD) and detox services and especially low barrier treatment approaches.
- **Stratification by Demographics**: Analyzing data by race and ethnicity is essential for understanding access disparities and improving outreach.

Overall, the workgroup emphasized the importance of improving data access and collection methods to enhance overdose prevention efforts and inform policy changes effectively.

#2 Qualitative and Ethnographic Research Workgroup

Question 1: What qualitative or ethnographic data collection methods are you currently using to conduct overdose-related research in MA? How can qualitative research help fill in the gaps that other types of research cannot?

Attendees employ various qualitative methods, including in-depth interviews, focus groups, social mapping, and Photovoice.

- **Ethnographic Techniques:** Observations help identify community hotspots, while "windshield ethnography" allows researchers to explore neighborhoods to inform data collection strategies. Initial observations are done without involving providers to reduce their burden.
- **Social Mapping:** Community members map out locations where behaviors take place, for instance, injection activities, which is a collaborative process that enhances engagement and data accuracy.
- **Photovoice and Daily Diaries:** These methods provide personal insights and narratives that enrich understanding beyond traditional research questions.

Qualitative research is crucial for documenting culturally competent practices and can lead to toolkits for harm reduction organizations, particularly valuable in the context of high staff turnover.

It helps in reaching populations often overlooked by standard healthcare approaches, allowing researchers to frame questions in community-relevant language for policymakers.

Training needs were emphasized by this workgroup. Staff, and especially community researchers who may be hired as fieldworkers, require training in qualitative methods, community engagement, and sensitive reporting to ensure ethical and effective data collection.

Question 2: What do you think are the gaps in overdose prevention research in Massachusetts? How could DPH help address those gaps through the use of or improvement to qualitative and ethnographic data? What recommendations do you have for summarizing data for policymakers?

- Community providers express frustration when researchers pursue grants without their input. Engaging these partners in research design is essential to align with their capacities.
- Qualitative Research Gaps: There's a need for more in-depth exploration of overdose prevention issues, with DPH encouraged to prioritize qualitative studies that deepen understanding of specific research questions.
- Trust issues exist regarding qualitative research; policymakers may question its objectivity and reliability. Clear methodology descriptions and a comprehensive presentation of data are essential to build trust.

Question 3: Based on everything we've discussed, what are some policy or research needs surrounding qualitative and ethnographic research?

- DPH should focus on integrating qualitative and ethnographic research into its annual priorities to provide nuanced insights.
- There's a call for better training in qualitative analysis and reporting standards, including presenting diverse quotes and themes to reflect comprehensive views.
- Mixed methods should be employed to provide a holistic perspective.
- There is enormous need for effective storytelling to change narratives around overdose issues. Engaging community voices can enhance understanding and empathy among policymakers.
- Suggestions also included interviewing constituents of policymakers to present community perspectives and ensuring findings are shared in accessible formats that resonate with the community.

Overall, the workgroup emphasized the importance of qualitative research in overdose prevention, advocating for collaboration with community partners, transparency in methodologies, and effective communication of findings to drive policy changes.

#3 Evaluation Research Workgroup

Question 1: What data sources/sets/collection methods are you using to conduct evaluations about overdose initiatives in Massachusetts?

- Existing data for evaluating overdose interventions is limited and often challenging to use, as seen with the HEALing Communities Study.
- Starting new datasets presents significant challenges, including maintaining data integrity and sustainability.
- Effective evaluation demands extensive primary data collection, which requires considerable resources and the right expertise, but funding is often limited.
- Evaluations of initiatives such as low-barrier housing face challenges such as delayed data, impacting the perceived effectiveness and sustainability of programs.

Question 2: Are there gaps in what information needs to be collected/shared and gaps in making a compelling case?

- **Importance of Storytelling**: Participants emphasized the power of storytelling through a research lens as an effective metric for dissemination.

- **Need for Broader Dissemination**: Information must be shared not only with leadership but also with frontline staff to ensure comprehensive understanding and engagement.
- **Collaboration on Results**: There is a need for collaborative efforts to share evaluation results, which should be presented in a digestible format.
- **Financial Support and Sustainability**: Participants called for increased financial support and clarity on reimbursement plans to ensure ongoing evaluation efforts, which are viewed as an investment.
- **Consistency in Evaluation Methods**: A consistent framework for evaluation methods is necessary, considering the changing nature of programs and services.
- **Focus on Prioritization**: While programs funded by BSAS are prioritized for evaluation, there is a concern that core services are often overlooked in favor of pilot and innovative services.

Question 3: What is driving the BSAS initiative to evaluate certain areas of research? Where are there areas for improvement?

- **Need for Clear Priorities**: Participants emphasized the necessity of understanding BSAS priorities, as current evaluations often feel reactive to external pressures rather than strategic.
- **Quality of Evaluation**: High-quality evaluations require time, and expectations for evaluation products need to be realistic and well-defined.
- **Focus on Non-Standard Metrics**: There is a need to evaluate non-standard metrics, such as microenvironments and hospital services for substance use disorder (SUD).
- **Distinction in Evaluation Types**: Participants highlighted the difference between BSAS evaluations and those conducted for other entities, stressing the importance of clear goals and expectations in partnerships with researchers.
- **Challenges with Current Evaluations**: Existing evaluations can be overly descriptive, miss long-term outcomes, and often lack qualitative data and consumer satisfaction insights. Additionally, reports may be difficult to interpret or lack tangible insights.
- **Flexibility in Evaluation Approach**: There is a need for evaluations to be flexible, adapting to insights gained throughout the process, rather than strictly adhering to initial questions.
- **Recommendations to DPH for Improvement**:
    - Establish a consistent evaluation model and cycle.
    - Identify key evaluation questions and funding mechanisms.
    - Improve sharing of data set availability and limitations to ease the burden on data collection.
    - Standardize evaluation methods across projects to ensure effectiveness.
    - Create a community research evaluation advisory group to set best practices and priorities.

Overall, the discussion highlighted the complexities and challenges of overdose evaluation, emphasizing the need for improved frameworks, better funding, and collaboration to enhance data collection and utilization in Massachusetts.

Action Points and Next Steps

DPH should have an annual research summit to review past-year activities and continue to refine the focus of overdose research. Conversations should evolve as research needs evolve, but should keep community engaged research as a foundational point.

- It is worthwhile for DPH to consider how to similarly convene other groups they work with

There should be an emphasis on being proactive rather than reactive: prevention and disparities should move to the forefront

- For example, we can be thinking strategically about a research approach that studies incident overdose and what are the touchpoints prior to that incident overdose. Regarding disparities, we should be examining what systems are people not touching, and who are the people who have no touchpoints in the year prior to dying from overdose?

DPH needs to better communicate and disseminate information both internally (e.g., information about what different groups are doing) and externally (e.g., sharing summarized data via dashboards, websites, and other data products).

- There is clearly a misunderstanding of what information is available for public/research use and exploration. **BSAS to do by July:** BSAS should release a summary of the available data sources so that people know what is available and how they are accessed, to convey the capabilities of the systems

DPH needs to synthesize and distill existing publicly available data for individuals with different data literacy, better translate data to communities, and provide summarized data that are widely accessible.

- For example, infographics are too little but sometimes dashboards are too much. Infographics often have an agenda, and are not a true summary of data. Dashboards are complicated and can be challenging to filter through.
- We need to ASK communities and other stakeholders what they think is important and ASK how they want to use the data. While RACK did so in the past, ECKS-O should ASK where people who use drugs get their information so we can provide data on those platforms (provide consumable data)
- Using this feedback (which should be ongoing), several different data dissemination products should be generated, not just one form and format.

DPH needs to think about the harm reduction workforce more critically, and what their role is in research.

- **BSAS To do by July:** DPH should considering creating a listerv of people interested in engaging in research to create the ability to reach out to those individuals as needed, but also consider ways in which to make the relationship mutually beneficial
    - For example, Community research partnerships can be used as a professional development opportunity (e.g., train individuals on how to do research) and provide payment for time/efforts

- BSAS should consider how to better support the workforce and understand what they need to feel supported
    - Data and ongoing input are needed here, where a workgroup approach could help bring community members and those with lived and living experience together to make recommendations from the beginning
    - We need to consider policies and training that impact the workforce, for example, EAP that offers harm reduction supports, job descriptions that allow for a return to use, human resources training that orients organizations to harm reduction workforce needs, etc.

- Access to MOUD is still a priority, AND BSAS needs to think about non-clinical based programming (behavioral health, wellness options) and how to assess their effectiveness and impact
    - BSAS needs to consider how to address the individual choice in treatment: cultural barriers to acceptance, what success looks like for different people, etc
    - BSAS needs to consider improved access to low barrier treatment, and how to measure if such low-barrier efforts to improve access are working (has access improved?)
        - BSAS needs to think about how the existing data systems and future data systems can help to identify and track **access to and use of low barrier treatment** (initiatives like 72 hour rule, mobile vans, emergency department-start injectables or other MOUD, initiation in prison/jail and transfer to care in the community, etc).
        - BSAS to consider integrating data across data systems (communication across systems and people to understand data better)
        - **BSAS to do by July:** Consider creating a work plan for defining, investing in and measuring low barrier care across different programs achieving this.
    - Think through how to leverage relationships with pharmacies, improve relationships with police, transition detox centers to incorporate MOUD induction

- Notably, there were gaps in conversations around integrating MOUD and harm reduction services robustly in community behavioral health centers, as well as in housing locations (recovery housing, housing first, permanent housing). It may be relevant to think more about these gaps.

- Data Efforts: Data need to be leveraged AND used to inform (social) policies and strategies, and BSAS needs to define measures
  - Quantitative: We need to better leverage DPH data sets, and utilize them for active surveillance
    - The touchpoints code that is being developed could be the basis for **annual reports** and may help identify more touch points.
    - We need to identify those without any touchpoints. DPH should strive to have common IDs across programs (e.g., Mobile Van, Faster Paths, Hub & Spoke) and large data sets to allow merging
    - **BSAS to do by July:** Look at overdose deaths by race and ethnicity, at-home/ housed at time of overdose death, and MOUD by race and ethnicity to understand disparities to inform policy and service
  - Qualitative and Evaluation Methods: Focus more effort on qualitative data for storytelling. Qualitative data are important to backfill quantitative data and drive policy changes. Consider standardization of evaluation: different projects across organizations will use different evaluation methods to ensure goals are met

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After reflecting and synthesizing information during and after the Summit, the Brandeis team suggested the following research questions:

1. **Understanding new phenomena:** What is driving the fall (and persistence/rise) of overdose rates in Massachusetts? How can rapid changes in the drug supply better inform our responses?

2. **Identifying At-Risk Populations**: Understanding the demographics of those affected by overdose
   a. How can we better identify and predict first overdoses?
   b. What is the touchpoint prior to an overdose, if any, according to the PHD? According to RACK?
   c. Who are the young people at risk of dying from overdose and what are their harm reduction needs?
   d. What are the overdose risk and harm reduction needs of other communities of people who use drugs via other mechanisms than injection (e.g., smoking, sniffing, buffing?

3. **Addressing Unwitnessed Overdoses**: Mine existing, past data (SUDORS, RACK, others) to understand factors surrounding unwitnessed fatal overdose. Prospective data collection (or intentional inclusion of questions on ECSK-O and other datasources) can inform interventions.

4. **Improving Treatment Accessibility**: Making treatment more patient-centered and expanding access through diverse venues like telehealth and pharmacies is vital. Future research questions should explore pilot and innovation projects on these topics and intersections.

5. **Supporting the Workforce**: Understanding and addressing the needs of those in the treatment and harm reduction workforce, including policy changes, is crucial for effective support.How can we better support the harm reduction work force and what is needed to feel supported? This is an ongoing and evolving question, not one answered once

6. **Critically Examining Transitions**: Transitions can be lethal (e.g., jail to community, hospital to community.) Think about how we can study continuity and transitions in care. Systems have been developed to help this process, but we need to measure them
7. **Timely policy-relevant analysis**: Ready datasets to be able to conduct policy-relevant queries and longer research inquiries. Invite partnerships and seek out researchers who may be interested in answering such questions, for instance, on Section 35 reform, limiting CPS involvement, expanding SNAP benefits, etc.