OVERDOSE PREVENTION RESEARCH SUMMIT 2024: SUMMARY REPORT

Prepared for the Massachusetts Bureau of Substance Addiction Services by Brandeis University: Traci Green, Mary Brolin, Joe Silcox, and Sarah Fielman

The Overdose Prevention Research Summit set to establish clear, evidence-based priorities for the Massachusetts Department of Public Health (DPH) in the areas of overdose prevention and drug user health. It aimed to reflect on past and current research efforts, identify gaps in knowledge, and chart a strategic course for future research activities. By bringing together researchers and policymakers, the research summit aimed to create a shared vision for the short- and long-term actions needed to address the opioid crisis and other related public health challenges in Massachusetts. Brandeis University hosted and guided the direction and execution of the research summit in collaboration with the DPH

Brandeis UNIVERSITY

COMMONWEALTH OF MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

BSAS Bureau of Substance Abuse Services

Prevent • Treat • Recover • For Life

www.mass.gov/dph/bsas

Contents

Current Data Sources

There are many different Department of Public Health (DPH) data sources that can be utilized to examine overdose and other aspects of the health of people who use drugs. Below is some very brief information about the data sources discussed during the summit. *For information on limitations on the data, as well as opportunities for use of data, see slide deck.*

Massachusetts Ambulance Trip Record Information System (MATRIS)

- A statewide database of emergency medical service (EMS) ambulance runs from over 300 EMS agencies. Every licensed ambulance service in Massachusetts is required to report detailed patient care records to the Department within 7 days of the encounter.

State Unintentional Drug Overdose Reporting System (SUDORS)

- Captures data on all unintentional and undetermined drug overdose deaths that occur in Massachusetts. The information included in SUDORS comes from a variety of sources including medical examiner reports, postmortem toxicology, medical records, and police reports.

Emergency Department (ED) Syndromic Surveillance (SyS)

- The data source for this analysis is emergency department (ED) visits from the National Syndromic Surveillance Program (NSSP) ESSENCE platform.

Registry of Vital Records and Statistics (RVRS) Deaths Data

- Provides data about MA births, deaths, marriages, divorces, and fetal deaths for use by government agencies, researchers, and the public. Death dataset includes data on deaths of MA residents including deaths by year, cause of death, and certain demographics of people who died.

Prescription Monitoring Program:

- Tracks patients who receive federally controlled medications from retail pharmacies in MA and mail order pharmacies across the country who ship to MA residents. Patients who meet certain multiple provider and pharmacy thresholds (i.e., activity of concern) have been used as a key indicator of program efficacy. The MA PMP also includes prescribed and standing order naloxone fills at pharmacies.
- Monitors trends in dispensing of federally controlled medications allowing the program to identify emerging concerns about certain types of medications that are reported to the MA PMP

Massachusetts Naloxone Programs:

- Includes data from programs that receive DPH-subsidized naloxone.
- Includes number of naloxone doses & FTS distributed, distribution encounters, and overdoses reported as reversed. This dataset is no longer actively collecting information about reversals, use, and refills; a passive reporting system will take its place.

Bureau of Substance Addiction Services

- Includes enrollment, assessment, and disenrollment information from clients admitted to a DPH licensed and/or funded program.
- There is a dashboard available

Massachusetts Public Health Data Warehouse (PHD):

- A tool that links multiple datasets across state and local governments to help address public health priorities with a focus on health and racial equity and social determinants of health

The Fireside Chat: Looking Back, Looking Forward

See attached grid information on group activity

Looking Back:

Question: What are key lessons learned about overdose from Massachusetts research?

- We need to partner with people who use drugs and their programs, and ask them questions
    - Equity requires work and resources
- Consider exploring other communities of people who use drugs (not only people who inject drugs) and other mechanisms of how people use drugs (e.g., smoking, sniffing, boofing, oral)
    - While exploring other communities such as these, consider investigating prevalence of overdose risk, morbidity and mortality risks for different groups, differences in risk across groups, risk of fatal and non-fatal overdosel, access to overdose education, and more
- Naloxone supply is changing, and what overdose looks like is changing and we need to think about our interests, needs, and tools (e.g., compassionate overdose)
    - In the setting of fentanyl, overdose deaths have tripled/quadrupled, and therefore we need to think about drug supply, contamination, and how it rapidly changes
    - We cannot focus on just one drug, it's critical that we understand the overall picture to be ready and address needs; we need to systematically collect data and use the data
    - Naloxone is necessary but not sufficient: Naloxone works for people who are witnessed when they use drugs. We need to continue to reduce unwitnessed drug use and make use safer to reduce overdoses.
    - Since COVID, 9-1-1 calls have been down, and understanding our non-fatal overdose trends are informative
        - Syndromic surveillance (SyS) data may help detect (early) signs of various public health trends. The data have the potential to allow us to have a more responsive overdose prevention approach, however, further work remains to make the data usable in this context
- We need to work to better leverage available resources and learn to work across organizations
    - It is hard to work with police, but it is hard to work without them. They are well funded and there are some who want to help and make a difference
    - Suggestion to develop and use data visualization tools to monitor real-time overdose and drug trends in an approachable way. These may compliment dashboards, which are beneficial for retrospective analysis.
        - Note, a law enforcement-based tool called OD map, an overdose mapping tool for quicker trend detection in MA, has not been reliably used in the past.
    - Consider how to better leverage pharmacies (and access to pharmacies); they are an important point in the care system
    - In addition to considering MOUD expansion and prescriber needs, we need to consider the harm reduction workforce priorities, capacity, professional development opportunities, and more to better and systematically support harm reduction programs and staffing.
- We need to understand geography (e.g., culture, local connections, drug supply) to better understand needs and shape programs (e.g., the needs of the Cape vs. Western MA vs Boston)
    - Location of OTPs should be considered
        - How much time does it take to get to them (walk vs. drive)? Does the amount of time to OTP impact access to treatment? Do we know the actual number of people who walk or drive?
            - See hyperlink to report titled Geographic Access to Community-Based Opioid Treatment Programs in Massachusetts
        - We need to better understand characteristics of those who access OTPs and what makes it hard to use them
- There is a lot of unknown/"in-between" in the quantitative/administrative data
    - We need mixed methods research and qualitative research to fill in those gaps.
    - There should be an emphasis on strategically using quantitative/administrative data to set research priorities and provide preliminary analysis and in turn we should use qualitative

data to provide more nuanced context. In using these research practices collectively data are more well-rounded and provide pathways for evidence-based decision-making.
        - We need to consider ways to share qualitative information (e.g., dashboard, storytelling, sharing codebooks, data repositories, etc)
            - Codebooks and qualitative data repositories may be beneficial for sharing data with other researchers who may be interested in conducting secondary analyses
            - A dashboard may be useful for, organizing, visualizing and monitoring qualitative data trends for non-researchers
            - Story Maps may be helpful for further exploring experiences, perspectives, and narratives more in an engaging and digestible way
    - We need to invest in qualitative data and data that do not emerge in our administrative formats
- There is a need to build strong relationships between funders and partners (e.g., the state and research partners, state and communities partners, research and community partners, etc).
    - Additionally, there is a need diversify/increase ways to access funding mechanisms for research to be funded and deployed quickly, and determine how to rapidly translate findings into policy and programming

<u>Looking forward:</u>
Question: What are key research priorities to better address overdose?

- Understanding the denominator is really important: Who are we talking about? Who is it that we are trying to help? Who is being helped and who is being harmed?
    - We could use the public health data (PHD) warehouse to understand who is at risk
        - Unwitnessed overdose is still a huge issue to address and we need to create processes and programs to reduce unwitnessed overdose
        - We do not have a good understanding of what non-fatal overdose look like but we do have a (somewhat) good picture of the fatal opioid overdoses
- We need to figure out how to make treatment work for patients, rather than patients work for treatment.
    - We need to have more choices and more venues like pharmacies, telehealth, SSP and mobile vans that can deliver MOUD
    - Transform detoxification centers into induction/initiation centers and expand agonist treatment
    - Consider a range of options: with new modalities of MOUD, such as XR-BUP, we need to explore perceptions, interest, intake, and access
- We should think about youth and young adults, and how to engage with schools, families, and treatment
- We need to lower barriers to access to treatment in jails (e.g., make sure people eligible for treatment get it) and use data to inform decisions
- Consider way to be predictive rather than reactive, and consider focusing on protective factors [broadly, such as primary prevention but also social determinants of health]
- We need to better support the workforce, and better understand what they need to feel supported
    - We need to bring in community members and those with lived and living experience, and we need to involve them in recommendations from the beginning;
    - We need to consider policies that impact the workforce, for example, job descriptions that allow for a return to use
- Rather than focusing only on access to MOUD, DPH should think about more health and wellness options for people who use drugs.

Community Engaged Research – Implementation:

RACK has generated insights that inform policy and services, measure local and state harm reduction needs, and identify areas of inequity. The RACK team has recommended expansion of syringe service programs, reforming Section 35, addressing stimulant use, providing fentanyl test strips and real time drug checking, and more

What is ECKS-O?

- ECKS-O was based on a variety of similar programs across the country, and includes feedback from community, research team involvement, appropriate compensation, time bound data collection, qual interviews, and focus groups.
- Aims to collect a variety of information about overdose, drug use, naloxone needs, and treatment options across MA
- Nurture the harm reduction workforce and create opportunities for direct involvement in data collection
- Comprised of self-administered surveys, interviews with key informants and participants, ethnographic observations, photovoice, and drug checking insights
    - HRAC indicated concerns of quality, completeness, literacy, languages offered of the self-administered surveys with PWUD, and process (use of coupons/RDS)

Review of Community Engagement Best Practices:

1. Meaningfully engage with the community as partners in research through piloting, community advisory boards, and understanding their topic of interest of communities
2. Build an effective research team by hiring people with lived and living experience, with appropriate skills and language proficiencies, and provide training and support
3. Embed research in the community, create multiple pathways for participating, ensure mutual benefits, build rapport with staff/orgs, understand community goals, and recognize partners and participants as experts
4. When analyzing data, be reflexive, use a team approach, ask for team feedback
5. When disseminating, share back information to the community, particularly in accessible forms and tailor information to increase engagement

Barriers indicated by community partners

In a survey to assess feasibility for annual data collection in MA Harm Reduction Organizations (n=20) the following barriers were identified by community partners:

- **Staffing:** Limited staff, difficulty finding funding to hire more people, not always sure if there is a person to serve as lead coordinator and contact for data collection
- **Physical space and payments:** No designated private space inside the organization to conduct surveys, regulations of physical leased space may not permit this work, and cannot safely store cash for paying participants/uncomfortable managing payments
- **Time:** People are stretched thin and do not have the necessary time to participate in additional research, and collect data above and beyond what they are already doing, or train new people
- **Buy-in from upper management:** Higher-level administrators at organizations need to approve participation of staff
- **Respondent Driven Sampling (RDS):** RDS is not a feasible recruitment method. It creates a large amount of pressure on the harm reduction team, coupons are not equitable, lack of end dates is challenging

Discussion generated ideas on addressing concerns of HRAC and the barriers indicated by community partners by considering a different sampling approach. Rather than using RDS or targeted sampling as in the past efforts, consider leveraging the PHD, SUDORS, and other datasets and programs of MDPH to recruit a proportional or stratified random sample of people who use drugs who are at risk of opioid overdose. Follow up discussions during the session, throughout lunch, and the days thereafter continued to explore this approach.

Work Groups:

Work Group 1: Administrative / Large Quantitative Data Sets
Facilitators: Dana Bernson & Chris Massad

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?

- You can directly go to CHIA (includes all payer claims data and MassHealth data) to get data
    - CHIA prioritizes government requests over research requests; this is not necessarily true for MassHealth (MassHealth does have to agree to provide the 42 CFR claims data)
        - CHIA is likely an underused resource because of challenges accessing it and issues using it. The data can be unwieldy to use even if it is very valuable
        - Work with your government partner on facilitating this process
    - Substance use related claims are 42 CFR part 2 protected meaning there are research protections and exceptions
        - To gain access to the information, DPH has an IRB covering the matching process (the matching process is the research) for the PHD
- If someone has ever had insurance but do not currently, they will be in the data but the data will only have the claims for the time period they were insured/covered (we will retain sociodemographic data)
    - It does not always include individuals on a self-insured plan (some groups voluntarily report but some do not)
    - For people who are incarcerated and lose insurance, we will not see any claims during their period of incarceration but we will see information from prior to incarceration
        - We do not have incarceration health data in the PHD
        - Jail systems don't have claims but they do have their own system for collecting health data
        - State office of pharmacy services provides medications and services to the jail, however, they do not have capacity to process the data
- **IMPORTANT Reminder: these data are a billing data set, not a health services data set**
- Changes in the system, for example like the change from ICD 9 to ICD 10, makes DPH questions how data are being translated and then used in trends (concerns of trusting data)

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

- There is a gap in understanding of how some infectious disease such as TB (e.g., other than HIV and HEP C) in conjunction with substance use may result in a catastrophic immune response and a public health crisis
    - Right now, the data warehouse can see data on Hep A, Hep C, HIV, and COVID
    - They have been most focused on adding other STIs to the data set, but hearing how TB could be an issue is helpful for DPH to consider
- There is a newly approved buprenorphine (bup) protocol (legislation passed in MA) that allows EMS to administer buprenorphine to help manage withdrawal after naloxone is administered to decrease refusal of transport to emergency departments (ED). No EMS agency has adopted this protocol. Importantly, MATRIS can track this data if protocol is used.
    - We need to find EMS partners who can implement the protocol and understand why agencies are not using the new protocols (e.g., capacity to train, money, etc)
    - We need to support EMS in building protocols, infrastructure, and roll out
    - Policymakers need to consider funding needs for new policies in order to have successful roll out
- We only have data about people who engage in services/appear in health and/or public systems
    - There are gaps in data from people who are not using services (such as EMS services)

- There is information that regularly gets reported in open narrative fields rather than in designated fields, and those free text fields need to be processed prior to adding to PHD because there is too much PHI
    - You can get a research exemption (DPH IRB) to go through the MATRIS data set (free text can be available there)
- There is a lot of variation in the care people receive and including facility codes may be helpful to include to understand variation
- DPH wants to promote non-punitive approaches to care such as Section 35 reform, substance exposed newborns program (DPH engagement instead of CPS) through reporting.
    - We need help to make a case for the policy change through data, but we need to think through how we can use the data to make policy changes.
        - PHD is great for understanding pre and post data – time series analyses
        - Can we create evaluation plans in advance and have that ready, and then be able to push those policies?
- We need to further think about the missing touchpoints, and how do we collect data for them
    - Some missing touchpoints: Department of Children and Families (DCF), housing, arrest data (data that does not result in jail), criminal/legal involvement, probation, and parole, discontinuation of medication in the context of other touchpoints, release from detox, etc.
- Consider how protected data can be generated from the existing data (e.g., getting a job, married, giving birth, etc.)
- DPH needs a better understanding if the resources they are providing to improve access are working. They need to see data to show increased access and improved care for MOUD, detoxes, etc.
- DPH needs to consider trajectory at the program and individual level
- There is some self-determination when it comes to people's choice in treatment. We need to think about reaching people to get them services they want.
- DPH needs to do more stratification, looking at race and ethnicity, and consider breaking it down into access and reach

<u>Work Group 2: Qualitative and Ethnographic Research</u>
Facilitators: Traci Green & Justeen Hyde

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 conduct in-depth interviews and focus groups as part of their qualitative and ethnographic research (informal and formal observation), as well as social mapping and Photovoice.
    - Ethnographic Research Details:
        - They conduct observations to identify hot spots and understand the context within a community.
        - When starting a new project, some do "windshield ethnography": drive around in a community to get the lay of the land, walk through a community at different times of the day and take photographs to understand the set up/context and to help identify where they should return for data collection and how they might sample respondents.
        - At first, this is done without involving providers at first to limit burden. After initial information is gathered, they go to community providers to get their input.
    - Social mapping is a method where researchers ask community members where the activity that is being studied is happening.
        - For example, asking community members and mapping where individuals get and discard injection supplies. They often map as the community gives them input and then share the maps back
    - Photovoice captures the viewpoint of stakeholders through images.
    - Daily diaries to give voice to participants and that this method often helps address specific research questions but also provides much more insight.

- Qualitative research methods are important in documenting indigenous and culturally competent practices.
    - Findings could be used to develop a toolkit for harm reduction organizations to use, especially given the high rate of staff turnover and the loss of institutional knowledge.
    - Qualitative research can be used with medical providers to demonstrate they have the knowledge and training to advise patients in harm reduction strategies.
- Qualitative and ethnographic research is important for representing people who are not reached via typical healthcare touch points, and allows for input on research questions in the language of the community, which can then be used by policymakers and practitioners to develop policies and services using that language.
- People doing field work, whether they are researchers or providers doing research, need training on qualitative and ethnographic methods, including how to work with community partners, how not to sensationalize findings, how to report sensitive findings (e.g., crimes), how to prepare good interview questions, how to take good field notes, how to work as a team through an iterative process to get to the truth and how to make decisions about what is helpful to report.

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?

- At times, community provider partners can feel frustrated and possibly taken advantage of when researchers write grants that require their data collection support or impact their programs without consulting them. It's important to include these community partners in designing and implementing research that fits within their programs' capacity to support the work.

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

- Attendees suggested that when DPH identifies a focus area/research question for the year, they should support qualitative and ethnographic research that explores that focus area/research question in depth, providing qualitative richness and detailed insights.
- There is work to be done to get policymakers and the community to trust qualitative research. There are concerns that policymakers and/or the community could say that qualitative researchers are "leading the witness" and "cherry picking" the best findings.
    - There is a need for good training for staff collecting and analyzing data, reporting that includes clear descriptions of the methods, and describing the use of standardized protocols and collecting data and coding to saturation.
    - Data reported needs to show a range of quotes for any given theme.
        - One idea was to provide a table of quotes by themes, include all quotes, or a larger number of quotes in an appendix OR, create a qualitative data dashboard or database.
    - Consider indicating in the report how many (e.g., a few, only one respondent) supported each particular theme reported.
    - There is value in using mixed methods to show findings from both the qualitative and quantitative viewpoints.
- There was discussion about NIMBYism and policymakers not caring about issues that affect the general public.
- There is a gap in "effective storytelling."
    - Qualitative and ethnographic research can help in this area, and help change the narrative by bringing in the voice of the community
    - Suggestion to interview constituents of specific policymakers to share the constituents' views with those policymakers (e.g., when citing services).
- We need to share back findings in a way that is accessible for the community, including providers and drug users.

- Find existing frameworks and translate the findings to the familiar to facilitate people's understanding.
- It is important to share findings with the community. It highlights the realities of what has been learned through qualitative research without sounding too academic.

Work Group 3: Evaluation Research
Facilitators: Scott Formica & Ranjani Paradise

Question 1: What data sources/sets/collection methods are you using to overlook overdoses in Massachusetts?

- There is limited existing data to use for evaluation and using existing data comes with its own set of challenges (example, HEALing Communities Study)
  - Starting a new data set is full of data challenges (e.g., methods are set up, and torn down, maintaining data is challenging)
- Evaluation requires a lot of primary data collection (takes time, energy, resources), the right people doing the work, and the sources are not long term sustainable (limited/lack of funding),
  - For low threshold housing sites, evaluation can be effective at meeting needs but there are barriers such as time lags in data
  - Challenge: a program may be found effective, but may not be sustainable

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

- Dissemination and storytelling are powerful: we tell stories through a research lens
  - It is an acceptable metric
  - Information needs to be disseminated to leadership but ALSO frontline staff
  - Needs to be collaboration on sharing back results, and results need to be digestible
- We need more financial support for evaluation research to more robustly and quickly assess effectiveness and impact of programs.
  - What is the reimbursement plan going forward?
- We need to consistently evaluate because things change over time and are not consistent.
  - Evaluation is an investment and therefore should be ongoing
- Sustainability is an issue
  - We need to think about the pieces of evaluation methods we can actually undertake, come up with an appropriate framework, use them consistently, and know when to use them.
- Programs fully funded by DPH are prioritized for evaluation
  - Core services do not get evaluated but pilot services, new services, and innovation projects get prioritized evaluation. It may be helpful to evaluate core/existing programs to identify areas that are working well and areas for improvement. Within this are challenges of capacity as some programs like MassHealth look to BSAS for evaluations

Question 3: What is driving the DPH initiative to evaluate certain areas of research?

- We need to know what the DPH priorities are because we are constantly responding to external stimuli, which feels reactionary
  - We need to consider the nature of evaluation and the expectations of the evaluation products. It takes time to conduct high quality evaluations..
  - Non standard metrics need to be evaluated (e.g., microenvironments, services for SUD in hospitals)
  - Consider development of an evaluation advisory board
- MassHealth relies on DPH to do their evaluation, but there is limited capacity
  - Generating reports and capturing people's experiences is not the same as evaluation.
  - Qualitative data and consumer satisfaction information are missing
- We need to think about the decisions we want to make, and then think about the data we need to capture to inform that decision (consider the program and the funder)

    - In partnering with researchers and evaluators, it is important that goals of DPH and the contracted parties are clear. They need not be overlapping, but should be discussed, with expectations from each articulated and revisited.
        - It is important to make a distinction between DPH evaluation vs. evaluation for other groups, and understand why and how changes in projects influence changes in evaluation
    - Decision making is nuanced and needs to be acknowledged
- Challenges with evaluation:
    - Can be too descriptive, longer-term outcomes and reach could be missing
        - Evaluate over time can help these issues
        - Sometimes data sources can help write the grants but are not useful to supporting evaluation outcomes.
    - Evaluation reports can be difficult to understand or not tangible
        - Sometimes there is no evaluation on a service (e.g., MOUD), but we need data to defend utility of services.
    - There is a fear from researchers that there is something wrong with the evaluation
        - It would be helpful to promote the cause even if there is a need to point out areas of improvement (this is in relation to low threshold housing)
    - The evaluation cycle and research cycle do not always coincide. While parameters may be identified from the outset, evaluators often learn the original model should not be followed , causing shifts in evaluation plan and unclear evaluation reports. Evaluation approaches may need to be flexible so that the original question is stated, answered or edited, and a revised question is posed and answered.
        - While we still learn information for the future (implementation, fidelity, etc), the original question posed for evaluation may not be answered
    - Community based research (in comparison to clinical research) needs to be more flexible
- Recommendations for evaluation:
    - We need to think about how we define success and consider using a consistent evaluation model “cycle” and/or having funding mechanisms that support these mechanisms
    - DPH needs to go to the drawing board to see what questions need to be asked, and consider their goals and priority topics
        - DPH needs to learn from these projects to inform strategy moving forward, including funding decisions
    - There needs to be appropriate funding for proper evaluation (funding is often limited)
    - Important to share information about data set availability, and convey their limitations to reduce burden of collecting new data and increase familiarity with existing data
        - Consider creating a common place to find information, have a data analyst who can share information related to the data, supporting data monitoring across data sets (DPH working towards)
    - Consider standardization of evaluation: different projects across organizations will use different evaluation methods to ensure goals are met. Data should help answer evaluation questions not just get grants.
        - We need to consider how we measure outcome variables
    - Establish a community research evaluation working or advisory group to establish best practices, set evaluation metrics and to help the DPH set evaluation priorities.