# Promises & Perils of Prescription Drug Monitoring Programs

Health in Justice Action Lab at Northeastern University in collaboration with the ACLU of Massachusetts

Workshop Report || April 13, 2019

## Overview

In the wake of the overdose crisis, all United States jurisdictions have rapidly adopted Prescription Drug Monitoring Programs ("PDMPs"). PDMPs electronically collect, monitor, and analyze controlled substance prescription information. According to the CDC, "PDMPs continue to be among the most promising state-level interventions to improve opioid prescribing, inform clinical practice, and protect patients at risk." These purported benefits have been elusive, however, while various shortcomings and pitfalls have received little scrutiny.

On April 13, 2019, the Health in Justice Action Lab, in collaboration with the ACLU of Massachusetts, hosted the half-day workshop *Promises and Perils of Prescription Drug Monitoring Programs* at Northeastern University. This interdisciplinary convening included researchers, health care providers, technologists, legal practitioners, and advocates, who applied clinical, public health, sociology, computer science, and patients' rights lenses to PDMP policy and practice. In addition to those attending the meeting in Boston, MA, attendees participated remotely via video link. This event was part of the Northeastern School of Law Center for Health Policy and Law's annual conference entitled The Promises and Perils of Emerging Health Innovations.

The focus of the workshop was to formulate strategies to maximize the benefits of PDMPs while minimizing harms.

Leo Beletsky, Professor of Law and Health Sciences and Faculty Director of the Health in Justice Action Lab, welcomed participants and provided a national overview of PDMPs.

Professor Beletsky presented an in-depth background of PDMP implementation and a legislative and legal status update on PDMPs in the United States. Professor Beletsky and his research team presented findings from their ethnographic and social listening project focused on provider and patient experiences with PDMP design, training, and data, summarized on the Action Lab website.

The Workshop consisted of "lightning talks" by participants on their research, legal, clinical, and patient perspectives. Given the dearth of critical examinations of PDMPs, participants voiced concerns about a number of areas where PDMPs may cause unintended detriment. These include harm to patients and providers as well as societal impacts related to inter alia privacy, use of PDMP data by law enforcement and other non-clinicians, fidelity and compliance in PDMP implementation, user-entered data accuracy, impact of PDMP on patient-provider relationship, role of private and government actors in PDMP administration, risk-scoring, and guideline development, statutory restrictions and changes, algorithmic fairness and transparency, clinical decision-making, "big data" implications, and the value of PDMPs as a public health tool.

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# Emergent Themes

Based on the diverse presentations and discussions, the following overarching themes emerged from the workshop:

### 1. The metrics of "success" for PDMP systems and policies have not been adequately defined.

• Given their roots as a tracking tool, the role of PDMPs in improving health was never concretely articulated or operationalized.

• PDMPs are count-based systems that use questionable quantitative measures as proxies for benefits safety, but these measures have not been critically assessed.

• Factors used in risk scoring by PDMPs and PDMP vendors are ironically structurally facilitated and perpetuated by use of the PDMP (i.e. the denial of prescription dispensation at a pharmacy due to concerns with the patient's PDMP score leads to a greater distance traveled between physician and pharmacy, which, in turn, leads to a greater PDMP score).

• When it comes to opioid prescription, law enforcement is playing a "squeeze game" (i. discourage and shut down prescribing and pharmacy sales, leaving entire towns and counties without access; ii. use PDMP surveillance to flag people for "traveling an inordinate distance" to get medications elsewhere).

• Adverse collateral harms of PDMP operations have not been well-defined or tracked.

• Defining and tracking harms is a necessary step to remedial and litigation efforts, which have been hampered by lack of research into specific instances of detriment flowing from PDMP policies and practices.

• The absence of quality utilization metrics has impeded training and other efforts to change prescriber practices relating to PDMPs.

### 2. Law enforcement access and privacy concerns

• Law enforcement currently has broad access to highly sensitive PDMP data, with unclear systems of checks and balances. This is not widely known to the American public.

• Warrant-less access to PDMP is widespread, and is subject to litigation by the ACLU and is also a target of state-by-state reform, supported by the AMA and other organizations. Warrant requirement is currently limited to roughly a dozen states. Whether it applies to federal law enforcement is an open question that is currently being litigated by the ACLU in the First Circuit's *Jonas* case.

• In Kentucky, Wisconsin, and Maine, PDMP data is bundled with criminal drug offenses.

• Statutory restrictions requiring warrants to access PDMPs are associated with steep declines in law enforcement requests for PDMP data.

• There are many open questions about the dynamics of law enforcement access to PDMPs, which the Action Lab is currently trying to answer with a national data gathering project utilizing FOIA inquiries.

• In the context of the overdose crisis, there has been a blurring of the roles between law enforcement, health care providers, and pharmacists. PDMPs have facilitated and operationalized this blurring. Care must be taken to avoid net-widening and adoption of enforcement functions into systems of care. This negatively impacts the provider-patient relationship.

• Child Protective Services and other agencies conduct investigations using PDMP data.

### 3. Special vulnerability (e.g. LGBTQ, chronic pain patients)

• PDMP disclosures and a lack of robust privacy protections disproportionately impact marginalized groups including transgender patients and those with histories of criminal justice involvement.

• Complex and rare disease patients are interpreted by the system as deviant, facing abandonment and barriers to medication and care access as a result.

• Treatment deserts in certain geographical areas mean greater distance traveled by patients, which are interpreted by algorithms as aberrant behavior. This in turn leads to patients denied treatment based on PDMP score because of distance traveled.

### 4. Design and systems flaws and limitations (i.e. decision support and care coordination)

• Prescribers face time constraints and other barriers in understanding risk scores and other information offered by PDMPs. Informational asymmetry and discrepancies in how specialty-dependent activities generate inequities (i.e. scoring for pain specialists should be different from primary care).

• In a climate of increasing opioid austerity and misapplication of CDC Guidelines, PDMPs become a tool for prescription suppression especially when the state believes few, if any patients should be on opioids, including cancer patients.

• It is highly problematic for PDMP alerts (to the providers as well as to oversight actors) to override clinical judgment. Methods of contextualizing data with health status as an indicator of success must be pursued.

• Algorithmic transparency is critical to meeting health-based (rather than arbitrary MME or other prescription value) metrics.

## Conclusions & Next Steps

Workshop participants concluded that efforts should be made to ensure that PDMPs are carefully and responsibly deployed as a tool to advance patient and public health. Further interdisciplinary research, implementation reform, and continued legislative and legal advocacy are needed to continually evaluate the interaction of PDMPs with other state-based laws and the impact of PDMPs on health and other outcomes. Recommendations:

1. Establish clear metrics of success focused on patient well-being;
2. Better functionality (i.e. care coordination, integration with EMRs) and provider training to align PDMP systems and policies with efforts to improve patient outcomes;
3. Improve privacy through design, legislation, regulation, and impact litigation.

To facilitate next steps, the Health in Justice Action Lab has submitted FOIA requests to all US jurisdiction and asked for all contracts, algorithms and risk scores, data aggregation and analysis, and law enforcement access and interactions related to the PDMP. These data will be used to better understand PDMP design, utilization and impact across the states. The Lab is also working with state partners to facilitate improved privacy protections for PDMP data in state law. Additionally, the Lab has created a listserv to enable further investigation and continued conversation post-workshop. Any interested person may request access to the listserv by emailing admin@healthinjustice.org.