

Exploring Unregulated Substance Use Health Data in Ontario, Canada: Identifying Gaps, Addressing Challenges, and Uncovering Opportunities

Overview

- Canada's overdose epidemic highlights the need for **high-quality, comprehensive, and timely** national health data to inform policies, targeted intervention strategies, and population health management.
- Currently, Canada lacks a coordinated national drug surveillance system to monitor unregulated substance use across jurisdictions.
 - Such a harmonized national system could improve early detection of emerging health threats, support population-level monitoring, and enable evidence-based evaluations of programs, interventions, and policy changes.
- Ontario is uniquely positioned as a leader in health data infrastructure in Canada, with the country's largest collection of administrative health data, strong governance frameworks, and data centres like ICES supporting secure, population-level data utilization and management.
- This study examined the current landscape of health data on unregulated substance use in Ontario through a scan of relevant datasets, literature, and policy documents.
 - We identified key gaps, challenges, and opportunities for a coordinated, equity-oriented, and comprehensive national drug surveillance strategy.

Findings

Landscape of Unregulated Substance Use Health Data in Ontario



Administrative Health Data

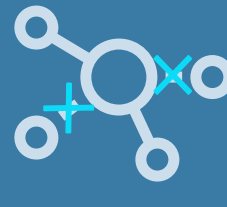
- Collected during healthcare interactions (e.g., hospital admissions, doctor visits, prescriptions, etc)
- Utilizes clinical coding systems (e.g., ICD-8 or ICD-9) to capture substance use-related harms and treatment outcomes
- Managed by data custodians designated under Ontario's privacy laws (e.g., ICES, Canadian Institute for Health Information [CIHI]) using provincial and national data systems
 - Examples: Discharge Abstract Database (DAD), Ontario Mental Health Reporting System (OMHRS), Narcotics Monitoring System (NMS)
- External access to these data for research and monitoring purposes requires formal applications and ethics reviews



Non - Administrative Health Data

- Typically collected through representative surveys capturing self-reported substance use, behaviours, and social determinants
 - Examples: Canadian Alcohol and Drugs Survey (CADS), Canadian Wastewater Survey (CWS), Ontario Student Drug Use and Health Survey (OSDUHS)
- Data are managed and shared by the organizations that conduct the research, in accordance with privacy and data governance laws, and data sovereignty principles
- Data are often shared publicly in aggregate form following data collection and analysis

Challenges Associated with Unregulated Substance Use-Specific Health Data in Ontario



Data Fragmentation & Redundancy

- Piecemeal data collection and management:**
 - Data is dispersed across multiple organizations, systems, and regions, resulting in siloed datasets that are difficult to locate, access, integrate, and consolidate
- Lack of standardization and interoperability:**
 - Different organizations, jurisdictions, and sectors use varying terms, metrics, methodologies, coding systems, and reporting formats
 - This leads to a lack of compatibility and interoperability across systems, making integrating datasets difficult
 - Limits the ability to compare and combine data across sectors, jurisdictions, and timeframes
- Redundant data collection and reporting efforts:**
 - Multiple sources may report on the same metrics (e.g., overdose deaths), often with conflicting numbers due to variations in data abstraction processes and timing
 - This results in discrepancies and creates confusion among public health planners, researchers, and community stakeholders



Data Gaps

- Data on substance use treatment:**
 - Data on treatment uptake and outcomes in Ontario are incomplete, especially from privately funded facilities, community-based services, and donor-funded programs, as these data are not captured in administrative health databases
- Data on specific population subgroups:**
 - Key populations, such as individuals experiencing homelessness, correctional populations, migrants/asylum-seekers, and racialized communities are consistently underrepresented in both surveys and administrative health datasets
- Social determinants of unregulated substance use and harms:**
 - Information on social determinants (e.g. justice involvement, housing, income) is often collected outside the health sector, and not consistently linked to health data, limiting a holistic understanding of the intersecting factors associated with substance use
- Data on ecological drug use:**
 - Limited data available on the types of drugs in circulation over time and by location, as well as population prevalence estimates of unregulated substance use, especially emerging drug trends
- Disaggregated data:**
 - Most available data are aggregated making it difficult to identify or tailor interventions based on intersecting identities or lived experiences
- Data on socio-demographic & equity characteristics:**
 - Data on race, ethnicity, and gender identity are often missing, or broadly categorized (e.g., "visible minority"), obfuscating health inequities



Data Lags

- Long lags between data collection and dissemination of data:**
 - Data dissemination can range from several weeks to over a year
 - Accessing data for broader research use requires complex and lengthy approval processes that can delay critical public health analyses
- Limited tools available to rapidly disseminate information on unregulated substance use and surveillance, such as sudden shifts in drug trends:**
 - Analyzed data are often published ad-hoc in academic journals and government reports, which are constrained by lengthy publication and editorial processes
 - By the time insights are published, they are too outdated to inform time-sensitive decisions or emergency response strategies

Recommendations to Strengthen Data Infrastructure and Support a National Surveillance System

1

Establish Data Standardization and Integration Across Sectors and Jurisdictions

- Create a national data dictionary to harmonize definitions, coding systems, indicators, and terminology**
 - Conduct regular reviews and update definitions and metrics to stay aligned with emerging drug trends and community-informed language
- Integrate health, social, structural, and multisectoral data to support a more comprehensive understanding of substance use and related harms**
 - Expand privacy and data governance frameworks to support secure sharing of data between sectors
- Strengthen data interoperability and linkage capacity to enable efficient integration of datasets across jurisdictions and organizations**
 - Modernize data infrastructure to support scalable linkage frameworks and real-time information exchange (e.g., common data platforms)
- Invest in local data capacity and workforce developmet to support sustainable survillance infrastructure**
 - Provide training and technical support in data linkage, privacy, and digital tools to build a skilled, equity-informed data workforce across regions

2

Improve Availability and Accuracy of Health Data on Unregulated Substance Use

- Engage People Who Use Drugs (PWUD) in the design of data collection tools and indicators**
 - Ensure that survey questions and other surveillance measures reflect diverse lived experiences by incorporating PWUD input on terminology, emerging substances, and patterns of use
- Adopt standardized socio-demographic data collection into routine clinical and health data systems**
 - Use safe, community-informed practices to collect detailed socio-demographic and identity data (e.g., race, gender, income, housing) to enable meaningful disaggregation of data and equity monitoring
- Partner with equity-deserving communities to guide inclusive data practices**
 - Work with racialized and marginalized groups to co-design culturally grounded data strategies that reflect their realities, promote data ownership, and uphold data sovereignty principles (e.g., OCAP)
- Invest in community-led data stewardship and capacity-building**
 - Equip local organizations and individuals from underrepresented and marginalized communities with infrastructure, training, and tools in data collection, analysis, and governance to support more inclusive, accurate, and representative data systems

3

Accelerate Collection, Analysis, and Dissemination of Timely and High-Quality Health Data

- Standardize and accelerate data reporting across jurisdictions**
 - Implement legislative or regulatory mechanisms to facilitate faster and more comprehensive reporting of substance use-related data
 - For example, in Arizona, United States, first responders and healthcare facilities are mandated to report overdose-related information within five days, enabling near real-time updates to their public dashboard
- Streamline data access and approval processes**
 - Establish clear, standardized procedures and role-specific training to minimize delays, reduce data entry errors, and increase transparency in data access within key data-holding organizations (e.g., ICES, CIHI, Statistics Canada)
- Foster sustained cross-sector collaboration and shared infrastructure to support real-time monitoring and evaluation**
 - Promote shared infrastructure and interoperable systems to enhance rapid data-sharing, longitudinal data linkages, and monitor cross-sector outcomes
 - Invest in national platforms and multi-stakeholder networks to scale data innovations and enable agile, evidence-based responses to emerging drug trends
- Invest in innovative tools and infrastructure for rapid and inclusive data collection and analysis**
 - Support adoption of novel and scalable approaches, such as wastewater analysis, machine-learning, social media surveillance, and internet-based surveys to improve the speed, reach, and comprehensiveness of substance use data