

# Data Challenges in Opioid Systems Modeling

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Meeting: Assessing and Incorporating Intervention Effectiveness in Systems Models of the Opioids Crisis

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# From last year...

- One-day event in Apr 2019, discussing data needs in opioid systems modeling
- 79 experts; 8 federal agencies and 16 research institutions:
  - addiction and opioids experts: 23%
  - modeling experts: 22%
  - data experts: 19%
  - senior government decision makers: 13%
  - decision scientists and health economists: 7%
- Full report (*AJPM*): [https://scholar.harvard.edu/files/jalali/files/data\\_needs\\_opioids\\_modeling.pdf](https://scholar.harvard.edu/files/jalali/files/data_needs_opioids_modeling.pdf)

Mohammad S. Jalali, Emily Ewing, Calvin B. Bannister, Lukas Glos, Sara Eggers, Tse Yang Lim, Erin Stringfellow, Celia Stafford, Rosalie Liccardo Pacula, Hawre Jalal, Reza Kazemi-Tabriz; *American Journal of Preventive Medicine*, 2020

# Major data challenges

# Current State

- No single data source offers all the qualities desired
- Definitions and measurement methods vary across data sources
  - hard to link different data sources
- Differences in data collection practices (and changes in those practices over time) make it difficult to distinguish true historical trends from reporting changes
- Available data often provide only approximates and are prone to errors and biases
- Major lag times for reporting
  - e.g., most recently published TEDS data is 2017

# Use, misuse, and use disorder

- Different data sources and literature are inconsistent regarding the definition and measurement of key variables and concepts
  - e.g., misuse/abuse/casual/non-disordered use, dependence/addiction/disorder
- Available data are difficult to interpret accurately
  - e.g., NSDUH has multiple Withdrawal variables – often difficult to know which to use
- Understanding incidence rates is critical to capturing and validating dynamics over time
  - Transition rates between use states are crucial for simulation modeling
  - Great need for longitudinal data collected on individuals (especially marginalized individuals)
- Mental health and incarceration are difficult to measure and model
  - Major surveys including NSDUH do not include incarcerated and institutionalized populations, missing a large group of opioid users

# Non-fatal overdose

- While data are available on nonfatal overdoses as independent events, they cannot be linked to individuals over time
- Poison control and EMS are not uniformly contacted when an overdose occurs
  - It is unclear how large the underreporting and overreporting margins are
- Data collection practices limit the accuracy of available proxies for overdose
- Limited data on Naloxone use, availability, and distribution efficacy

# Illicit opioid supply and demand

- Limited data available regarding sources, volume, and price of illicit opioids
  - StreetRx which is often the only source available has a likely more substance naïve pool of individuals who report purchases leading to biases
- Because of different policies surrounding DEA action, it is difficult to disentangle kgs seized and general "drug bust" increases from initiatives to seize more
- Trends in heroin initiation and escalation are complex and changing over time
  - NSDUH data (gold standard) are incredibly noisy as the absolute sample sizes of heroin users are very small, leading to users of certain underrepresented groups being highly weighted
- Estimating opioid diversion nationally should be a priority

# Treatment utilization, outcomes, and relapse

- Inconsistent definitions and measurement of key treatment variables
  - e.g., retention/duration, successful discharge, relapse, remission
- Limited and interspersed data on treatment history, relapse, and sustainability
- Lack of data on interaction with the criminal justice system, polysubstance use, comorbidities, social determinants and social influences
- Available data are often limited by small sample sizes in controlled trials
- TEDS data are on individual treatment episodes so people cannot be tracked over multiple interactions with medical system
- certain data collected by N-SSATS are only collected every other year or every several years leading to gaps

# State vs. national level data

- States have made major progress over the last decade to provide more up-to-date and granular data
- Yet, there is much room for improvement and filling the gap
  - Dashboards often have significant lags
  - Misclassification of deaths is dependent on local coroner practices and can result in large scale under/over reporting of suicides vs. unintentional overdoses
  - Inconsistent testing for fentanyl in different regions
  - Some states fail to report to TEDS entirely

**What should be done**

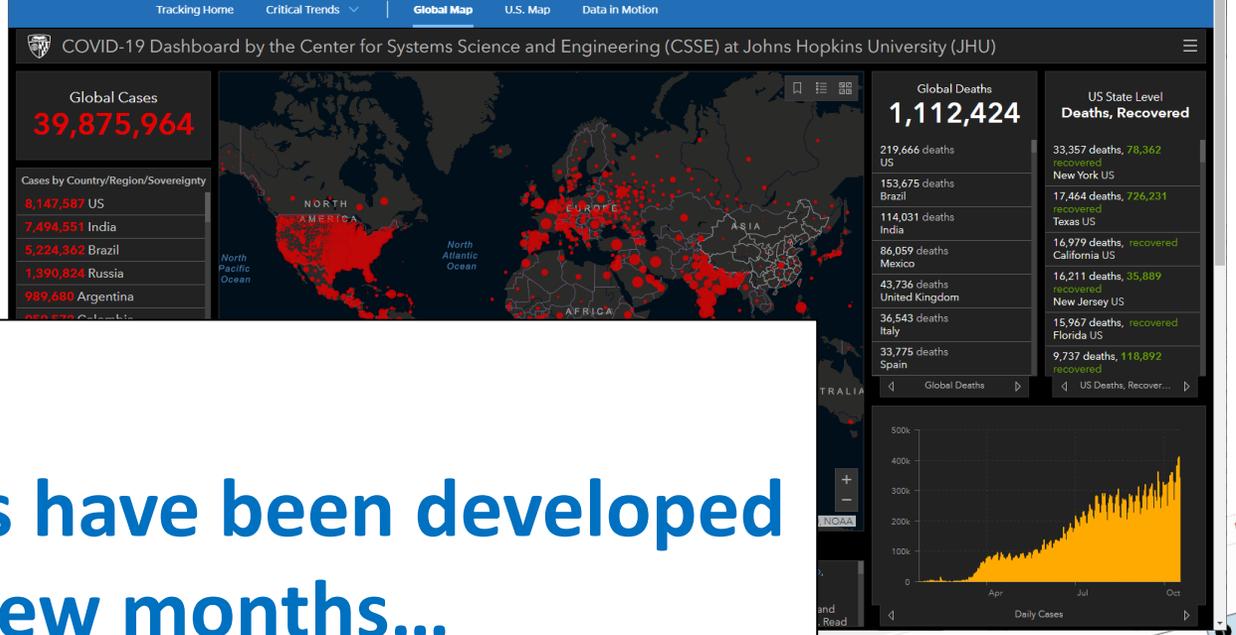
# Next steps for modeling teams

- Engage in direct and regular interaction between modelers, data experts (and providers), and public health experts
- Maintain close, direct, and regular collaboration among modeling teams
- Gain a clearer definition of policymakers' research questions and policy goals

# Potential paths forward to address data challenges

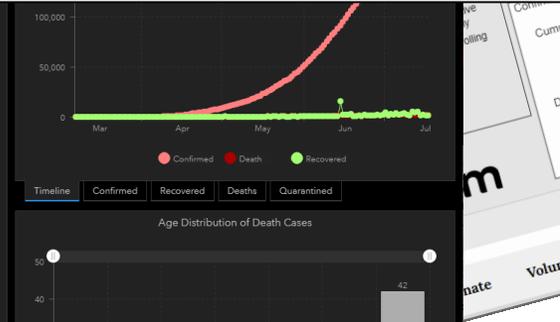
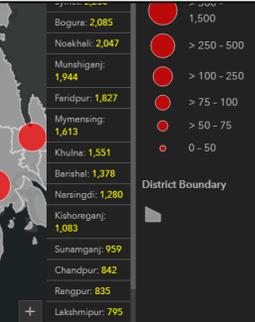
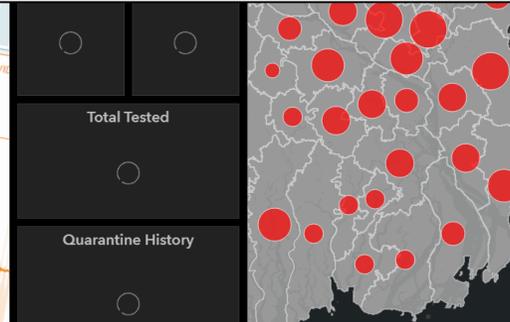
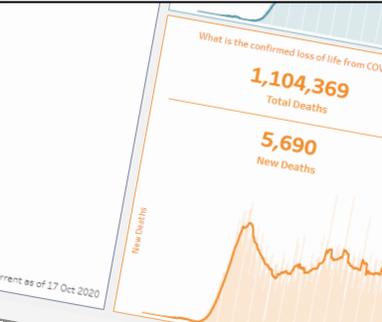
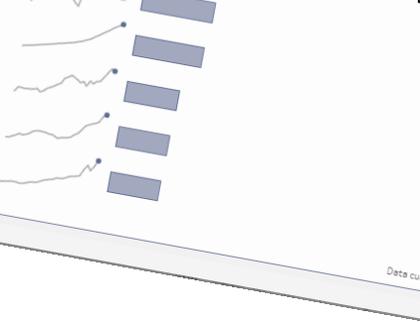
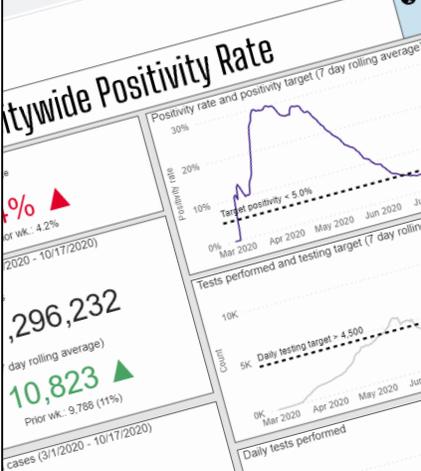
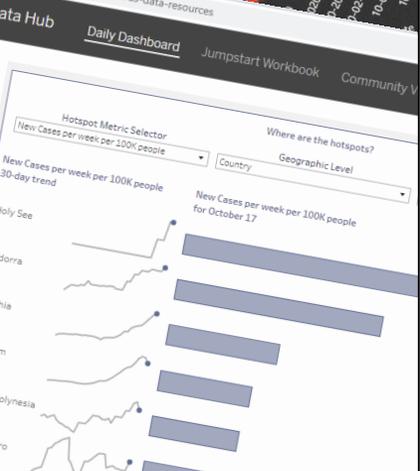
- Generation of a standard list of definitions for prioritized terms and variables
  - a dedicated workgroup may be the appropriate avenue for this discussion
- Incentives for states and providers to encourage submit the data more completely and frequently
- Facilitate linkages of multiple data sources at the state and national levels
- Enhance data sharing
  - making computable forms of data publicly accessible by data providers
- Develop data dashboards

# Two ongoing epidemics...



Hundreds of dashboards have been developed for COVID-19, only in a few months...

How many *up-to-date* dashboards do we have for opioids, after two decades?



# (Suggested) Discussion Questions

- What approaches should stakeholders take to increase the availability of standard definitions for key variables across data sources?
- What data limitations must stakeholders address first to enable the development of representative systems models? Further, what types of data are essential to the development of trustworthy models of the crisis?
- What novel data sources should HHS and partner organizations consider integrating into existing systems models to increase model validity and reliability?
- How has the COVID-19 public health crisis impacted the quality and availability of data for model integration?
- Can HHS and partner organizations repurpose or repackage existing data from other sources to inform modeling efforts? If yes, which sources?

# Reference

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