Data Harmonization and The Role of Common Data Elements in Scaling Harm Reduction Research

National Academies of Sciences, Engineering, and Medicine Workshop on Harm Reduction Services for People Who Use Drugs: Exploring Data Collection, Evidence Gaps, and Research Needs

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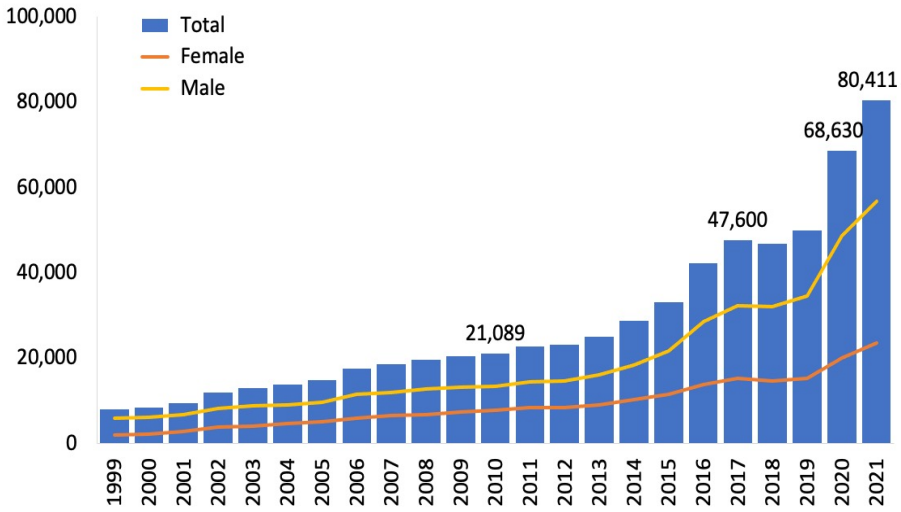
Outline

- Landscape of Harm Reduction Research
- Data Harmonization for Scaling Harm Reduction Research
- Challenges in Data Integration and Interpretation
- The Importance of Common Data Elements (CDEs)
- Developing and Implementing CDEs in Harm Reduction Research
- Data Sharing and Collaboration
- Considerations for Greater Adoption of CDEs and Data Harmonization
- Closing

Harm Reduction Research and the Case for Data Harmonization

- With the escalating opioid crisis, expanded access to harm reduction services is crucial to improve outcomes for people who use drugs (PWUD)
- Research needed to generate evidence in support of harm reduction intervention
- Data from varied sources exist
- Opportunities exist to harmonize data for collaborative data sharing and large-scale analyses to generate robust evidence
- Limited understanding of long-term outcomes of interventions
  - **Need for standardized data collection and harmonization to strengthen evidence**

Figure 3. National Overdose Deaths Involving Any Opioid*, Number Among All Ages, by Gender, 1999-2021



*Among deaths with drug overdose as the underlying cause, the "any opioid" subcategory was determined by the following ICD-10 multiple cause-of-death codes: natural and semi-synthetic opioids (T40.2), methadone (T40.3), other synthetic opioids (other than methadone) (T40.4), or heroin (T40.1). Source: Centers for Disease Control and Prevention, National Center for Health Statistics. Multiple Cause of Death 1999-2021 on CDC WONDER Online Database, released 1/2023.

Source: National Institute on Drug Abuse. (2023, June 30). Drug Overdose Death Rates. National Institutes of Health. https://nida.nih.gov/research-topics/trends-statistics/overdose-death-rates

Data Harmonization for Harm Reduction Research

- Data harmonization involves the process of *bringing together data of varying sources, formats, standards, and definitions into a cohesive, consistent, and usable dataset*

  - Can facilitate data integration and analysis across different studies, enhancing robustness of evidence

  - Useful for identifying broader patterns, trends, and outcomes of harm reduction interventions

  - Support for evidence-based policy making and the development of best practices

Challenges in Data Integration for Harm Reduction Research

- Differences in methods, measures, and a lack of data standardization
- Variability in data quality and completeness can skew interpretation and conclusions
- Limited scalability due to non-comparable data
- Data sharing and collaboration challenges because of privacy concerns, data use limitations, interoperability challenges
- **Clear need** for a standardized way of measuring research constructs for harm reduction

  => Common Data Elements (CDEs)

Common Data Elements (CDEs) for Data Harmonization

Common Data Elements (CDEs) are *standardized, uniform data collection terms and definitions used consistently across different studies and research projects*

- Enables consistent data collection, coding, and classification for data harmonization
- Facilitates data comparability and interoperability for sharing across different studies
- Enables meta-analyses and systematic reviews
- Supports replication of research studies
- Data more **FAIR**- **F**indable, **A**ccessible, **I**nteroperable and **R**eusable

Existing CDEs not well tailored for harm reduction research (e.g., PhenX Toolkit, NIH Toolbox, PROMIS, etc.)

Need for concerted development and adoption of CDEs, specifically for harm reduction research

Steps for Implementing CDEs for Harm Reduction Research

Identify key harm reduction research areas that would benefit most from CDEs

Establish standards for data collection, processing, and storage

Collaborative engagement and partnership development

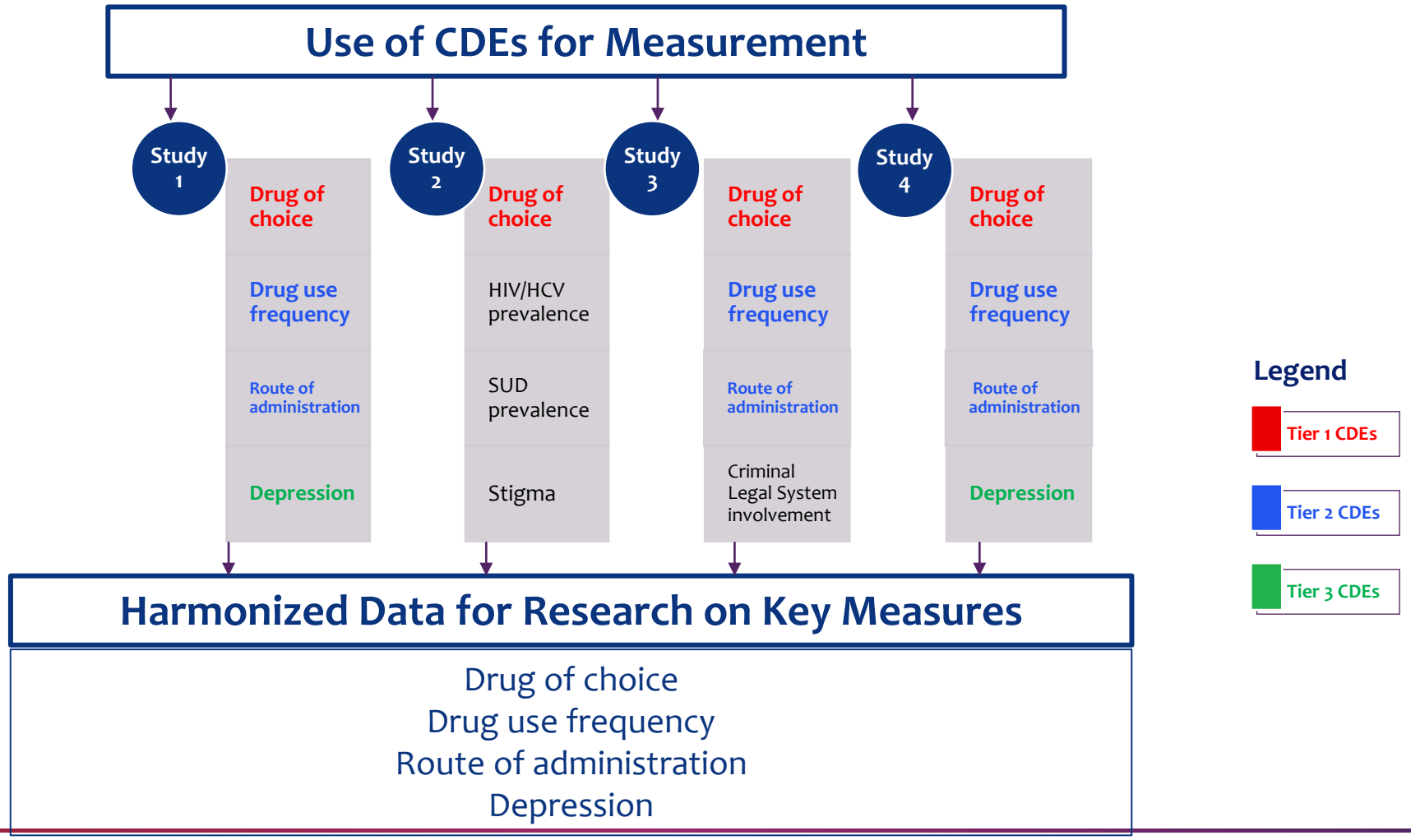
Collaborate with researchers, practitioners, policymakers, and people with lived experience, when possible, to ensure CDEs are relevant and practical

Monitor implementation of CDEs

Adapt and refine as new research findings emerge, and the field of harm reduction evolves

Share best practices to encourage broader use of CDEs

CDEs and Data Harmonization Use Case



CDEs for Data Sharing and Collaboration

CDEs provide a common language for data, simplifying communication and exchange between different research groups

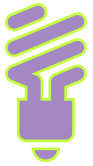
Facilitates partnerships across groups and studies by removing barriers to data integration

Promotes multidisciplinary research and the combination of diverse expertise, enriching the scope and depth of studies

Shared data for repositories and platforms with enhanced accessibility and transparency (as allowable based on data privacy concerns, DUAs etc.)

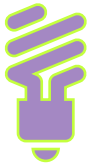
Challenges and Considerations

Standardization



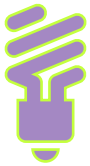
Consensus through expert panels, interdisciplinary collaboration, and stakeholder feedback

Privacy and Confidentiality: Data Sharing Concerns



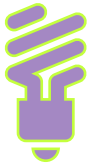
Strict data governance policies, deidentification, and secure data sharing platforms

Resistance to change



Provide training, facilitation, and evidence of the benefits of CDEs to encourage adoption

Funding and Resources



Seek funding specifically for CDE integration; demonstrate cost-effectiveness of standardized data collection

Closing

CDEs Adoption for Data Harmonization Supports Data Sharing, Archiving, and Cumulative Science for Scaling Harm Reduction Research

- Increased research efficiency
  - ➢Faster data collection, analysis and dissemination
- Expanded research scope
  - ➢Enables exploration of new and under-researched areas
  - ➢Sample size gains for detection of low-signal phenomena
  - ➢Validation of measurement constructs
- Reliable and comparable data for policymakers and practitioners

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Thank you

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