Data Linkage Helps Researchers Find Patterns in Opioid Use and Treatment Response among Patient's Hospital Encounters

Data on Mortality, Hospital Care, and Drug Use Provide a Fuller Picture of the Opioid Crisis

The U.S. is experiencing a historic epidemic in opioid use, abuse, and overdose. National-level statistics on opioid-related hospitalizations are limited and often incomplete. Patient-centered outcomes research (PCOR) on the epidemic requires building a robust data infrastructure of contributing factors, including the types of drugs being abused, co-occurring mental health and substance use issues, mortality, as well as information about how care is delivered across the health care system.

While systems to collect this information already exist, the data are often not linked at the individual or patient level. Uniting these data through linkages creates a more complete picture of the patient. For example, the clinical electronic health records (EHR) data and claims data that are generated from an emergency department (ED) visit will be missing a key piece of outcomes data if the patient dies of an overdose outside the hospital at a later date. Likewise, outpatient EHR data may document other mental health or substance use issues. Therefore, linking these data with enhanced mortality data adds critically needed information on the cause of death and the specific opioid involved.

These linkages enhance the value of individual data sets for research and knowledge generation, especially for opioid use research where data tend to be scattered and urgently needed.

The National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC) undertook three projects to address these data infrastructure needs. Since 2017, through the Office of the Secretary Patient-Centered Outcomes Research Trust Fund, NCHS has integrated multiple data sources to build innovative data resources that will improve researchers' ability to analyze data on hospital care, co-occurring mental health and substance use issues, post-acute care delivery, and deaths related to opioid-involved overdose. Through utilization of these integrated data resources, researchers can gain insight on patient characteristics, patterns of care, and other risk factors that affect health outcomes in cases of opioid misuse or abuse.

Newly Linked Datasets, Data Collection, and Reporting Tools Support Enhanced Patient-Centered Outcomes Research

The three CDC projects leveraged data from the National Hospital Care Survey (NHCS) as well as the National Death Index (NDI). NHCS is the only federal health care establishment data system designed to collect patient personally identifiable information, which is necessary for linking hospital encounters to administrative data sources such as the NDI to obtain cause-specific mortality.

The first project (2017) produced new capabilities to generate benchmarks of clinical outcomes such as death following hospital discharge at 30, 60, and 90 days by linking NHCS data to NDI data. The linkage also allows for comparison of inpatient to ED discharge outcomes (such as readmission or mortality) for specific causes of death. In addition, the NHCS was linked to the Centers for Medicare and Medicaid Services' Medicare Master Beneficiary Summary File (MBSF) to generate estimates on opioid-related health care utilization and expenditures in the elderly and disabled U.S. population following hospital discharge.

The second project (2018) expanded data capacity for PCOR on opioid misuse and overdose by: 1) improving opioid-identification in hospital visits by utilizing EHR clinical notes, 2) creating a new research data file with generic names of specific opioids involved in ED visits, hospitalizations, and deaths, and 3) developing data collection and reporting tools to support research on hospital encounters involving opioids.

The third project (2019) focused on building data capacity for PCOR by identifying co-occurring mental health disorders among opioid users using the linked hospital care and mortality data. Mental health disorders occur among many opioid misusers and is considered an important risk factor for morbidity and mortality among this population. Also, the project validates the performance of two sets of algorithms (one set identifying opioid involvement and one set identifying co-occurrence mental health disorders), applies any enhancements needed to the algorithms, and informs the creation of additional algorithms for other diseases and conditions using similar techniques.

Anticipated Impact

By linking these data sources, researchers will be able to identify specific opioids involved in outcomes, such as drug-related hospital visits and drug poisoning deaths. Expanding access to these data will allow researchers to retrospectively analyze trends in patient hospital encounters (e.g., post-hospitalization mortality), populations (e.g., Medicare patients), and specific opioid agents. The project is also developing improved research techniques and algorithms to generate knowledge that informs national-level strategies for improving hospital care and preventing opioid-related mortality.

PCOR QUESTIONS THIS PROJECT HELPS TO ANSWER:

Who dies of fentanyl overdose? As a population, are people who die of fentanyl overdose different from people who die of heroin overdose?
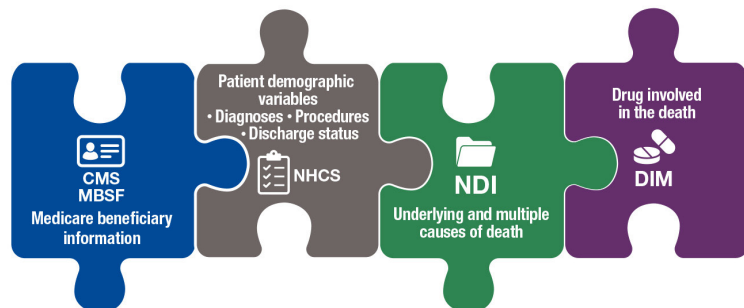
Which opioid-using patients have a co-occurring mental health disorder? Are they different from opioid users without a co-occurring mental disorder?

What hospital care did opioid-using patients receive in months prior to overdose death?

Following hospitalization for opioid use, does the risk of post-discharge mortality differ by type of mental disorder?

Are patients with co-occurring mental disorders at a greater risk for repeat hospital visits?

A Comprehensive Clinical Dataset Needs Linkage Between Data Sources

Each data source has valuable information. When pulled together, the data linkages provide a fuller picture of the opioid epidemic.

PROJECT ACHIEVEMENTS:

Publicly Available Products and Presentations	Brief Description
Datasets linking NHCS data to the NDI	This linkage allows researchers to track mortality up to a year after the hospital visit. Due to confidentiality requirements, the linked NHCS-NDI data are accessible only through the NCHS Research Data Center (RDC). All interested researchers must submit a research proposal to the RDC. Please see the RDC website for instructions on submitting a proposal (https://www.cdc.gov/rdc/index.htm). Also available on the **CDC website** is the report that describes the methods used for linkage, contents of the linked datasets and analytic guidance to assist researchers using the NHCS data linked to the respective NDI dataset.
Dataset linking NHCS data to the MBSF	This linkage provides the opportunity to conduct a vast array of studies on health care utilization and expenditures in the elderly and disabled U.S. population. Also available on the **CDC website** is the report that describes the methods used for linkage, contents of the linked datasets and analytic guidance to assist researchers using the NHCS data linked to the MBSF. Due to confidentiality requirements, the linked NHCS-CMS MBSF data are accessible only through the NCHS RDC.
Dataset linking NHCS, NDI, and DIM data	In addition to information on 2014 NHCS inpatient and emergency department visits and 2014-2015 mortality information, this file includes information on specific substances and drug classes mentioned on the death certificate. Also available on the **CDC website** is the report that provides analytic guidance to assist researchers using the NHCS data linked to the NDI dataset linked to the drug-involved mortality (DIM) file. Due to confidentiality requirements, the linked NHCS-NDI-DIM data are accessible only through the NCHS RDC.
Presentations at the 2020 International Conference on Health Policy Statistics	The linked NHCS and NDI data were used in the poster, "Mortality for Women Within 1 Year After Delivery in the National Hospital Care Survey, 2016". **https://ww2.amstat.org/meetings/ichps/2020/onlineprogram/AbstractDetails.cfm?AbstractID=306772**
	The linked NHCS and NDI data were discussed in the presentation, "Identification of Opioid Involved Health Outcomes Using Linked Hospital Care and Mortality Data". **https://ww2.amstat.org/meetings/ichps/2020/onlineprogram/AbstractDetails.cfm?AbstractID=306607**
	The linked NHCS-NDI data were used as part of a case study in developing synthetic data, "Using Synthetic Data to Replace Linkage Derived Elements, a Case Study". **https://ww2.amstat.org/meetings/ichps/2020/onlineprogram/AbstractDetails.cfm?AbstractID=306675**
National Hospital Care Survey Demonstration Projects: Opioid-involved Emergency	This NHCS report demonstrates the utility of linking the 2014 NHCS, 2014-2015 NDI, and the 2014-2015 DIM data to study opioid-involved ED visits, hospitalizations, and mortality within 1 year post-discharge. Example research questions and unweighted results are presented. Results are not nationally representative.

LEAD AGENCIES:

The Centers for Disease Control and Prevention (CDC): This project is a collaboration between the Division of Health Care Statistics and the Division of Analysis and Epidemiology at the National Center for Health Statistics (NCHS), within the CDC.

MEET THE PROJECT TEAM:

Holly Hedegaard, M.D., M.S.P.H.
Injury Epidemiologist
Division of Analysis and Epidemiology
National Center for Health Statistics
Centers for Disease Control and Prevention

Geoff Jackson
Hospital Care Team Leader
Division of Health Care Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention

Carol DeFrances, Ph.D.
Acting Director, Division of Health Care Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention

Lisa Mirel
Chief, Data Linkage Methodology and Analysis Branch
Division of Analysis and Epidemiology
National Center for Health Statistics
Centers for Disease Control and Prevention

For more information, visit:

aspe.hhs.gov/enhancing-identification-opioid-involved-health-outcomes-using-linked-hospital-care-and-mortality-data

aspe.hhs.gov/identifying-co-occurring-disorders-among-opioid-users-using-linked-hospital-care-and-mortality-data-capstone-existing-fy18-os-pcortf-project

aspe.hhs.gov/enhancing-data-resources-researching-patterns-mortality-patient-centered-outcomes-research

ABOUT OS PCORTF

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS PCORTF) is a portfolio of approximately 50 projects, including the projects spotlighted in this document, to build data capacity for PCOR on topics such as opioids, value-based care, mortality data, real world evidence, and the interoperability of electronic health records. Managed by the Office of the Assistant Secretary for Planning and Evaluation, the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, OS PCORTF provides for the coordination of relevant federal health programs to build data capacity for comparative clinical effectiveness research, including the development and use of clinical registries and health outcomes research networks, in order to develop and maintain a comprehensive, interoperable data network to collect, link, and analyze data on outcomes and effectiveness from multiple sources including electronic health records. To learn more, visit https://aspe.hhs.gov/patient-centered-outcomes-research-trust-fund. For questions, please email OSPCORTF@hhs.gov.