ACTIONABLE DATA FOR ADVANCING KENTUCKY TOGETHER

Heather M Bush, PhD

Dean

College of
Public Health

DATA MEET THE LAND GRANT MISSION

- **KIPRC (Kentucky Injury Prevention and Research Center)**: KIPRC collects, analyzes, and translates data into direct policy impact, such as informing legislation on injury prevention and safety. We analyze and report this data directly to state agencies and legislative committees.

- **RADOR (Research and Data Organization Repository)**: Federally-funded, university infrastructure demonstrates our capability to securely manage, curate, and make accessible complex research datasets. It's a blueprint for integrating multiple data sources into a comprehensive platform

- **MEDICAID** (July 2025) contracts for program evaluation research and improving the effectiveness, economy, and the quality of services delivered to Medicaid beneficiaries; provide technical and analytical expertise on the identification, migration, and integration of multiple disparate data sets into a data warehouse environment

- **DBHDID** (July 2025) contracts support the design and implementation of research and information systems for the Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID) and facilities (14 Regional Community Mental Health Centers, State Mental Health Hospitals, and community clinics).

RADOR-KY OVERVIEW

- Developed with NIH-NIDA Funding
  - No Licensing Fee, Open Source
  - Agnostic to the data type
- Designed to serve as a central analytical hub, complementing and enhancing existing state agency efforts, not duplicating them.
  - Reduces redundant efforts across various agencies
  - Ensures consistent, high-quality analysis
- Developed in collaboration with 3 UK research centers

With support and input from state agencies and organizations, including:

- KY Cabinet for Health and Family Servies
- KY Justice and Public Safety Cabinet
- KY Board of Emergency Medical Services

University of Kentucky

CHOOSE DIFFERENT GEOGRAPHIC OR ADMINISTRATIVE LEVELS
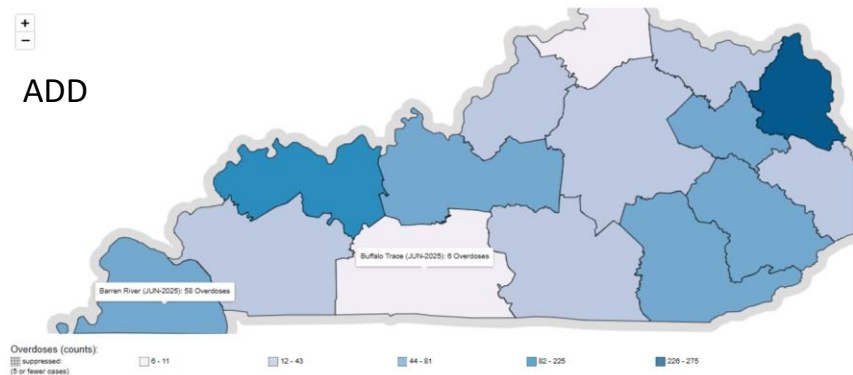## (State, County, ADD, Local Health Department, and Community Mental Health Centers)

ADD

Health Department Service Area
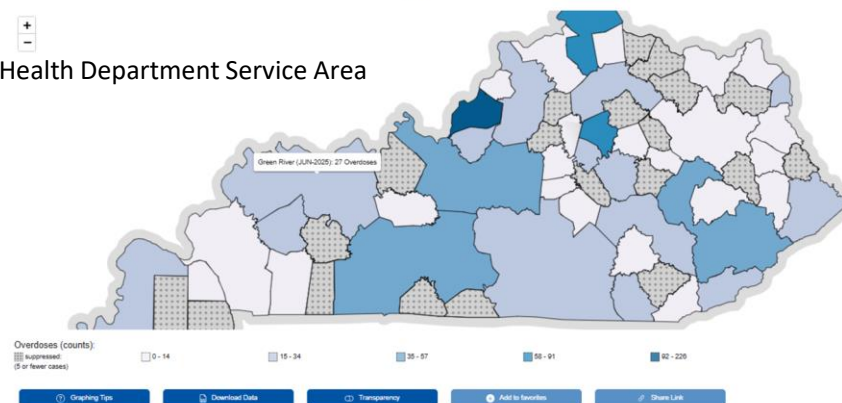
VIEWS ALLOW SUPPRESSION OF SMALL COUNTS

IDENTIFY EMERGING HOT SPOTS
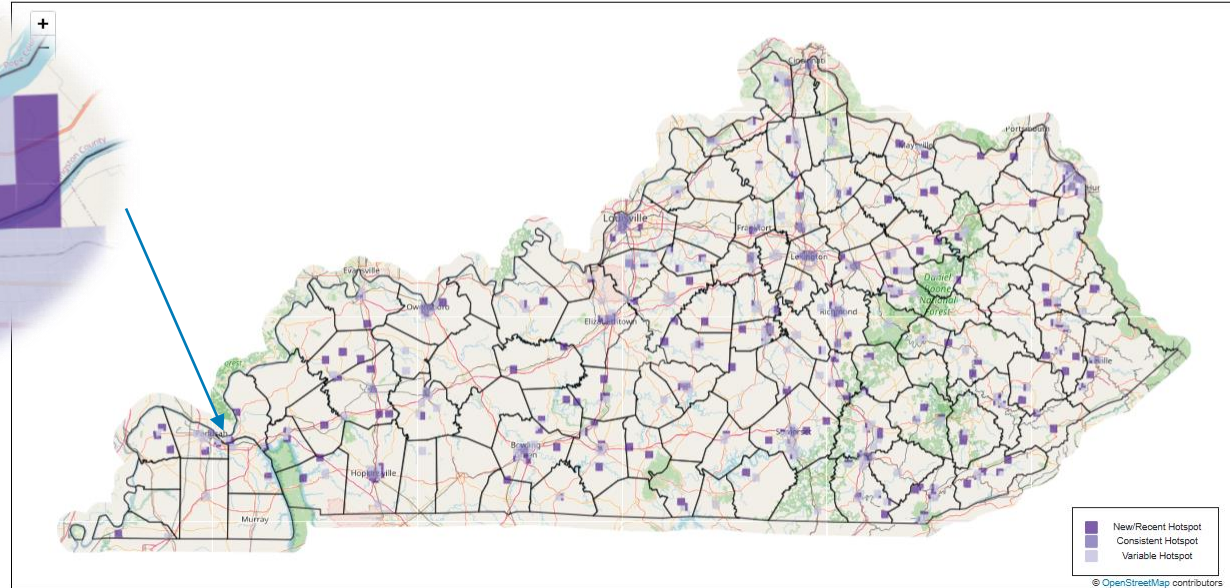
FORECAST OPIOID OVERDOSES TREATED BY EMS
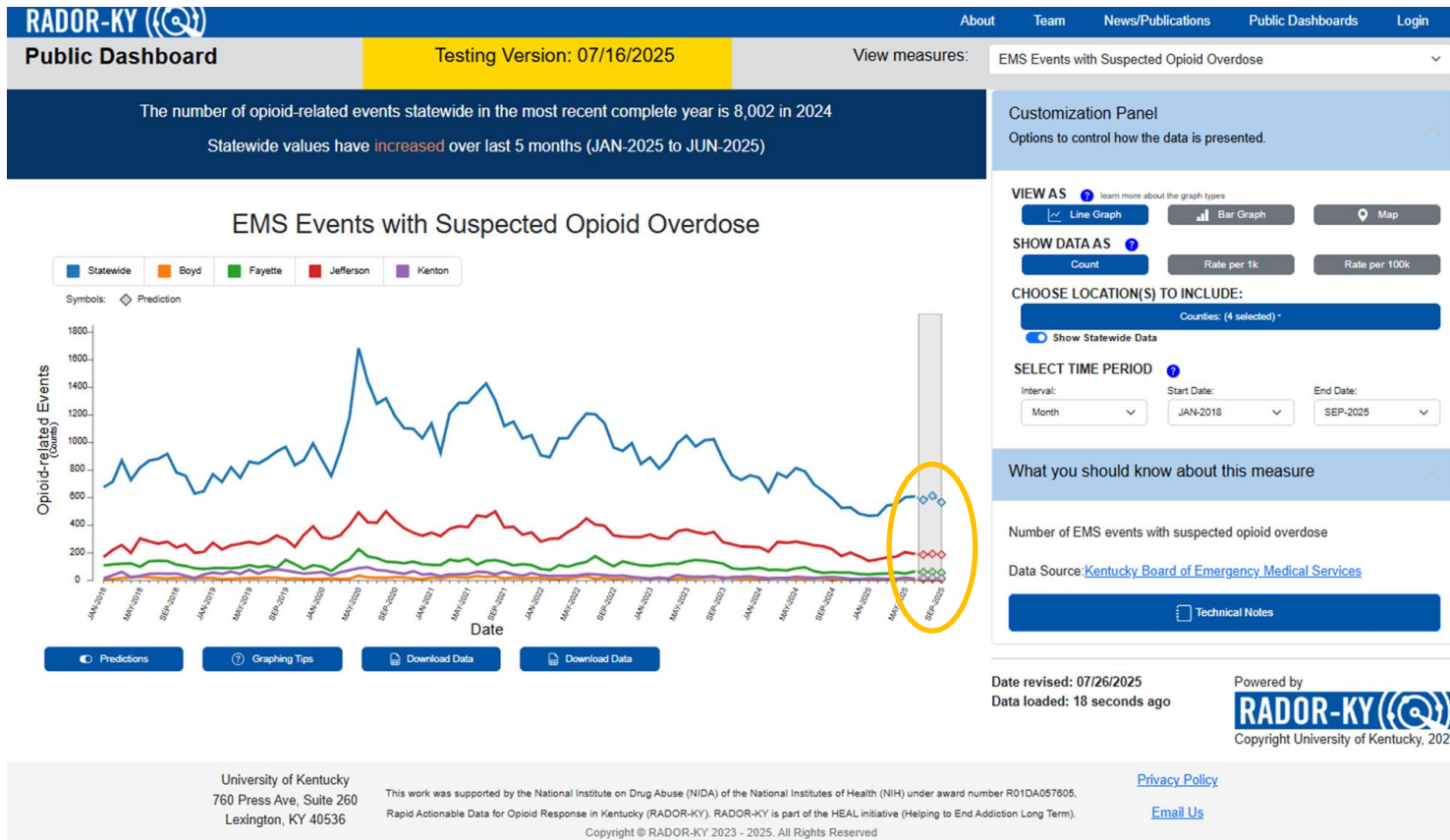
NEW FUNCTIONALITIES

Our team is always looking for ways to improve how we share actionable data – and to make our tools easier to use!

What we are currently working on

- Custom Dashboards; User Groups with **Login Access**
- Visualization/Dissemination of Agency-generated Data (**public or with a restricted user access)**
- Using AI to make the user experience better, such as assisting with user navigation among hundreds of measures and dashboards
- **Sharing** our tools and expertise with community and state partners

The Kentucky Cancer Registry: Providing Data and Information for Evidence-based Decision Making

Eric B. Durbin, DrPH, MS

Associate Professor, Division of Biomedical Informatics, College of Medicine
Director, Cancer Research Informatics Shared Resource Facility
Director, Kentucky Cancer Registry
Markey Cancer Center
University of Kentucky

Interim Joint Committee on Health Services

July 30, 2025
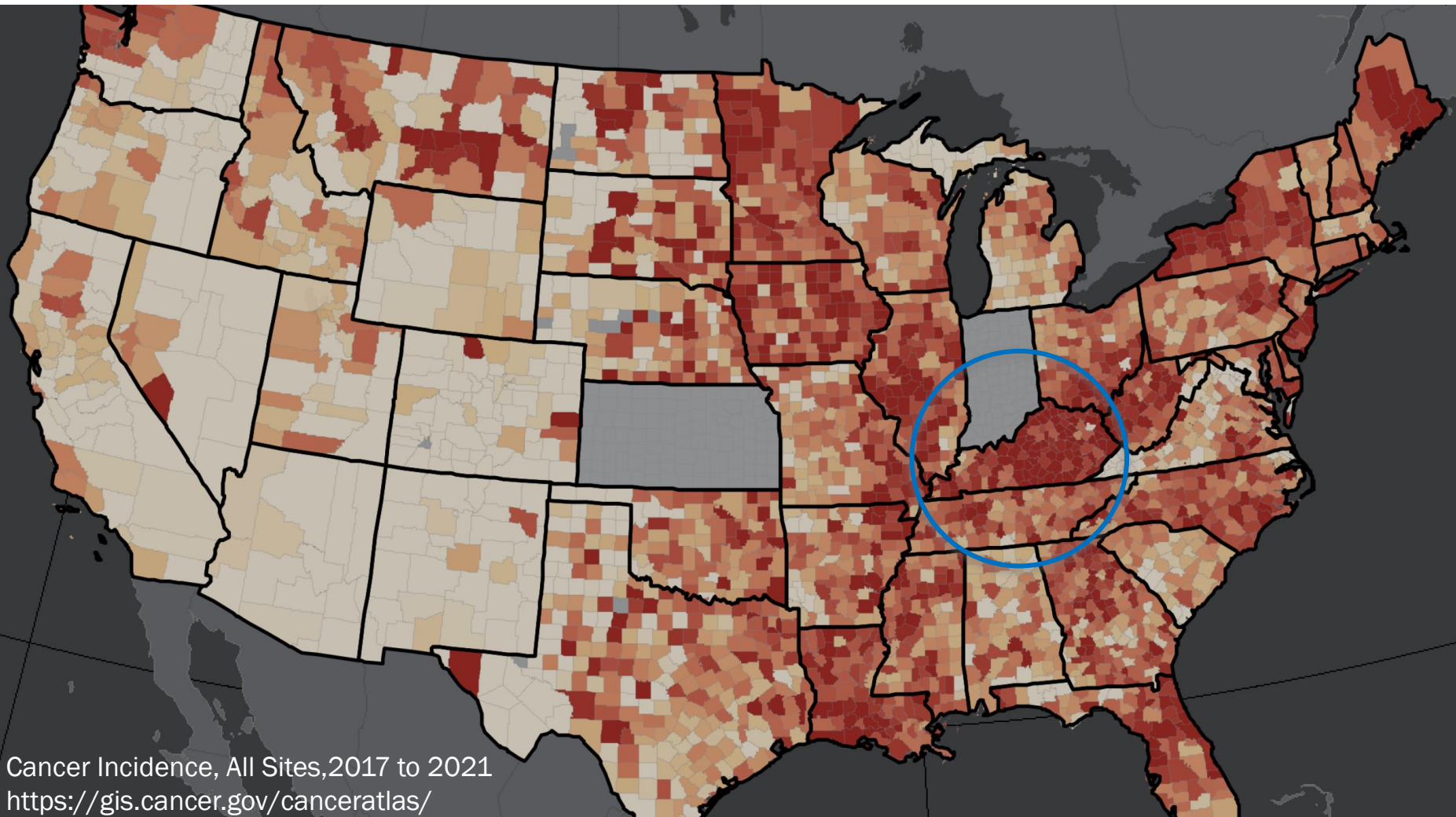
Cancer Incidence, All Sites, 2017 to 2021
https://gis.cancer.gov/canceratlas/

How Do We Know the Burden of Cancer in the United States and Kentucky?

- Through active population-based cancer surveillance programs in all states and most U.S. territories

- Cancer is a reportable disease mandated by state laws
  - Kentucky: KRS 214.556
  - Kentucky Cancer Registry (KCR) established at the UK Markey Cancer Center in 1990
  - Facilities that diagnose or treat cancer patients "shall report to the Kentucky Cancer Registry, through the cancer patient data management system and in a format prescribed by the KCR, each case of cancer seen at that health facility..."

- Funding
  - Commonwealth of Kentucky (22.0%)
  - CDC National Program of Cancer Registries since 1994 (16.2%)
  - NCI Surveillance Epidemiology and End Results (SEER) Program since 2000 (61.8%)

- Data sharing for evidence-based decision making and research is fundamental to KCR's mission

Kentucky Cancer Registry (KCR) Data Sharing

- Keys for effective health data sharing
  - Standardized data collection
    - North American Association of Central Cancer Registries (NAACCR)
  - Ensuring high data quality: accuracy, completeness, timeliness
  - Protecting patient confidentiality
  - Providing multiple avenues for painless and widespread access to data

- KCR data sharing (https://www.kcr.uky.edu/research/)
  - Hospitals manage and retain their own data as it is collected for reporting to KCR
  - Public website: http://cancer-rates.com/ky
    - Age-adjusted cancer incidence and mortality for all cancer types, sex, race, year(s), Kentucky geographies
  - SEER*Stat Analytic Platform: All KCR de-identified data available to qualified researchers who attest to proper use
  - Prepared presentations: Area Development District cancer counsels, Kentucky cancer screening programs, cancer advocacy group meetings, legislative meetings, research meetings, publications, etc.

- Research access through a formal application and review process
  I. Aggregate data
  II. De-identified records
  III. Data linkages and partially identified records such as geolocation
  IV. Support for patient contact studies
  - Institutional Review Board (IRB) approval required, in accordance with level of patient risk

Future Vision for Broader Cancer Data Sharing and Use

- National initiatives in Electronic health record (EHR) collection and data sharing
  - NIH/NCI
    - National Childhood Cancer Registry
    - NIH Data COUNTS – data reported to NIH collected once, appropriate for multiple uses
    - National Clinical Cohort Collaborative (N3C): New cancer and nephrology data enclaves

- Regional and local data sharing initiatives
  - Appalachian and Inner-city Pediatric, Adolescent, and Young Adult Cancer Data Ecosystem (ACCELERATE) Consortium: Integrated molecular and clinical data sharing in Appalachian states (KPCRTF)
  - Cancer Research Data Commons: cBioPortal access to fully de-identified molecular and clinical diagnostic and outcome data for cancer researchers
  - Expanded use of KHIE

- National data standards Initiatives
  - Minimal Common Oncology Data Elements (mCode): increase interoperability through core set of data elements
  - United States Core Data for Interoperability (USCDI+) Standardized EHR data capture for use by cancer registries, clinical trials, and adverse event reporting (FHIR interfaces)
  - Observational Medical Outcomes Partnership (OMOP): common data model to standardize and facilitate analysis of healthcare data

Questions/Discussion

- Contact Information:

  Eric B. Durbin, DrPH, MS

  Director, Kentucky Cancer Registry

  Telephone: 859-218-3182

  E-mail: ericd@kcr.uky.edu

  Web: http://www.kcr.uky.edu

Childhood Cancer
in Kentucky

2013-2022

INTERIM REPORT

https://www.kcr.uky.edu/childhood-report/