



UTAH DEPARTMENT OF  
**HEALTH**

# Disease Registries

October 19, 2020

# Data is the lifeblood of public health



## Data Types

- Demographic
- Cost
- Disease-specific/Diagnosis
- Behavioral
- Process/Procedural
- Outcome
- Treatment/Intervention/Prevention effectiveness

## Purposes

- Surveillance
- Needs assessment
- Monitor & predict trends
- Identify disparities
- Assessing risk factors and co-morbidities
- Resource allocation
- Prevention & intervention effort
- Evaluate program efficacy
- Cost-effectiveness
- Grant applications

# MISSION & VISION



The Utah Department of Health's mission is to protect the public's health through preventing avoidable illness, injury, disability, and premature death; assuring access to affordable, quality health care; and promoting healthy lifestyles.

Our vision is for Utah to be a place where *all* people can enjoy the best health possible, where *all* can live and thrive in healthy and safe communities.



# STRATEGIC PRIORITIES



**Healthiest People** – The people of Utah will be among the healthiest in the country.

**Optimize Medicaid** – Utah Medicaid will be a respected innovator in employing health care delivery and payment reforms that improve the health of Medicaid members and keep expenditure growth at a sustainable level.

**A Great Organization** – The UDOH will be recognized as a leader in government and public health for its excellent performance. The organization will continue to grow its ability to attract, retain, and value the best professionals and public servants.

# What is a disease identification system?



- “A tool for tracking the clinical care and outcomes of a **defined patient population.**”<sup>1</sup>
- A registry is a collection of information about individuals, usually **focused around a specific diagnosis or condition.** Many registries collect information about people who have a specific disease or condition.<sup>2</sup>
- Used to increase understanding of the disease, trends over time, comorbidities, course of disease, outcomes, etc.

1. Agency for Healthcare Research and Quality. "[Computerized Disease Registries.](#)"

2. <https://www.nih.gov/health-information/nih-clinical-research-trials-you/list-registries>

# What registries does UDOH oversee?<sup>1</sup>



- Utah Cancer Registry
- Utah Registry of Autism and Developmental Disabilities
- Parkinson's Disease Registry (defunded on 7/1/2020 )
- Stroke
- Cardiac
- Birth Defects
- Newborn Screening for Critical Congenital Heart Defect
- Traumatic Brain Injury (in the process of being set up)
- Trauma Registry & Pediatric Trauma Registry
- Blood Lead Registry
- Baby Watch Early Intervention

<sup>1</sup>Note that this list may vary depending on how you define disease registry

# Spending by Funding Source for Registries



- **Federal Grant Funds**

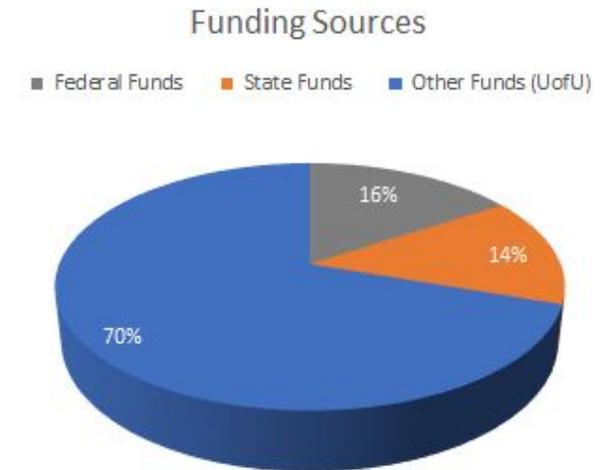
- Birth Defects/Congenital Heart Defect -\$62,000
- Baby Watch Early Intervention - \$315,000
- Blood Lead Registry - \$25,000
- Traumatic Brain Injury (registry set up fund) - \$91,988

- **General (State) Funds**

- Stroke & Cardiac - \$30,000
- Parkinson's Disease Registry - \$101,600 for FY20
- Utah Registry for Autism and Developmental Disability - \$94,900
- Pediatric Trauma - \$215,000

- **Other Funds (non UDOH)**

- Utah Cancer Registry (UofU federal funds) - \$1,768,035
- Utah Cancer Registry (UofU funding) - \$396,221



# Similarities/Differences



## **Similarities**

Demographic information

Reporting to CDC if federally funded

## **Differences**

Different platforms/technology

Who can access

Who reports

Other information

# Steps towards Improvement



- Strategic focus of Health Information Technology (HIT) at UDOH
- Integrated multiple communicable reporting systems into a single secure web-based disease surveillance system, EpiTrax.
- Use of existing systems to populate registries

# Common Data Model



- A CDC Informatics Fellow is working to identify commonalities in data elements across several data systems in UDOH and determining the degree of concordance between values in these data systems and national common data models/standards.
- Anticipated outcomes are:
  - Identifying where UDOH may be able to combine some systems.
  - Identifying where UDOH can leverage information to populate multiple registries to reduce duplication and reporting burden.

# Efforts to Streamline Disease Data Collection



- Working with internal/external stakeholders to create chronic disease reporting rule to streamline collection of chronic disease data for public health monitoring.
- Collaborating with UHIN to build infrastructure to enable UDOH's programs to use the CHIE data warehouse for public health data needs.

# Conclusion



UDOH is assessing where systems may be able to be combined or coordinated for efficiency.

Questions?