

HB199 S1 - Health Data Amendments

Rep. Norm Thurston & Sen. Kirk Cullimore

The Utah Health Data Authority was established in 1990 to collect data that informs the public, policymakers, and decision-makers about the quality and cost of healthcare in Utah. This data serves critical functions, including:

- **System Planning:** Informing hospital systems about opportunities for future planning.
- **Medicaid Evaluation:** Evaluating the performance and value of Medicaid accountable care plans.
- **Regulation:** Assisting in the regulation of health insurance companies.
- **Quality Reporting:** Reporting on the cost and quality of care provided by healthcare systems.
- **Employer Support:** Helping employers structure plans to focus on high-value care.
- **Public Health:** Documenting statewide trends in disease prevalence and chronic conditions.
- **Innovation:** Providing benchmarks to promote private-sector competition.
- **Accountability:** Identifying fraud, waste, and abuse, and monitoring patient safety incidents.

Strengthening Operations and Governance

Following a **2025 OLAG performance audit**, HB199 modernizes the Health Data Authority by eliminating antiquated language and requiring the Department to maintain publicly available strategic plans for:

1. **Data Collection:** A roadmap for what data is gathered and why.
2. **Comprehensive Data Management:** Standards for how data is handled and stored.
3. **Analysis and Dissemination:** Clarifies how sensitive data can be used within the department and by local health entities and strengthens those provisions.

Enhanced Privacy and Security Protections

HB199 incorporates significant safeguards to ensure Utahns' health data remains secure and private. These enhancements include:

1. Data Governance & De-identification

- **Expanded Identifiers:** Adds more items to the formal list of "direct identifiers" to ensure more robust anonymization.
- **Anti-Re-identification:** Strengthens statutory language to strictly prohibit attempts to re-identify individuals in the dataset.
- **Local Authority Limits:** Clarifies that local health entities may use data for public health purposes but **may not** receive direct identifiers.

2. Accountability and Liability

- **Downstream Liability:** Explicitly specifies that downstream users of the data are liable for damages resulting from misuse or breaches.
- **Data Deletion:** Requires users to delete data immediately when it is no longer needed or at a pre-specified expiration date.
- **Opt-Out Integrity:** Ensures that individual "opt-out" requests are honored by all downstream users, not just the primary department.

3. Transparency and Oversight

- **Security Policies:** Strengthens the requirements for internal security protocols and data handling.
- **Mandatory Reporting on Security and Privacy Plans:** Requires the department to include specific updates on health data privacy and security as part of their regular **Privacy Program Report**.