

¹H.B. 41: Key amendments of Title 26B Chapter 8 Part 5, Utah Health Data Authority [Act]

Effective Date: May 1, 2024*

Extended Sunset Date: July 1, 2026

The sunset date related to the Department of Health and Human Services' health data authority has been extended to July 1, 2026. This extension ensures the continuity of statutory functions and responsibilities as cited within statute.

These amendments realign the committee's and department's roles and responsibilities concerning the collection, management and utilization of data collected under this Act.

1) Definition changes:

- "Control number" means a number or other identifier that:
 - (a) is assigned by the department to an individual's health data;
 - (b) is consistent with the best practices of data privacy; and
 - (c) is used to ensure health data is not able to be readily associated with an individual when the health data is provided for research or statistical analysis.
- "Disclosure" or "disclose" means the communication of health care data to any individual or organization outside the [committee] department, its staff, and contracting agencies.

2) Transferred health data authority duties:

- The Health Data Committee's role has been modified to advise and consult with the department related to the department's duties under Chapter 5, Part 8, Utah Health Data Authority.
- Duties cited under the Act become the responsibility of the Department of Health and Human Services (DHHS) with the consultation of the committee.

3) Health data handling and data usage restrictions:

*except actions affecting Section 53-2d-203. Data Collection, which takes effect on July 1, 2024.

- Directs the department to use the minimum necessary data for its duties and restricts the use of personally identifiable information to specific uses in line with statutory purposes.
- Forbids the department from sharing any part of an individual's social security number obtained through APCD or HFD data submissions with any other person or entity.

4) Opt-out system:

- Mandates the creation of an opt-out system by DHHS which allows individuals to have their identifiable health data suppressed or restricted from accessibility for departmental duties.
- Requires the department to maintain a list of individuals who have opted out and use it in accordance with the opt-out provisions.
- Mandates that instructions for the opt-out system be conspicuously provided on the department's website.
- Prohibits the department from sharing, analyzing, or using any identifiable health data from individuals who have opted out, including data previously obtained.

5) Annual privacy practices reporting:

- Instructs the department to report annually on its privacy practices and efforts to enhance data privacy to the Health and Human Services Interim Committee.

6) Review of health data mandates:

- Directs the department to review and report on state statutory mandates related to health data collection, with a focus on mandates older than ten years, assessing their continued relevance and utility This is to be done before October 1, 2024.

7) HDC membership and requirements:

The composition of the Health Data Committee has been modified to aid in aligning the committee's expertise with evolving health data governance needs within Utah.

- Political affiliation requirement removed: Restriction of how many Governor appointed committee members may be of the same political affiliation was struck.
- Committee members increased from 15 to 19, with the addition of the following seats:

- i) Two legislators appointed jointly by the Speaker of the House of Representatives and the President of the Senate;
 - i) One advocate for data privacy appointed jointly by the Speaker and the President, and
 - ii) One public member with knowledge regarding data privacy appointed jointly by the Speaker and the President.
- Quorum increases from 8 to 10 committee members for the transaction of business.