

**17b-59d**  
**Statewide Health Information Exchange**  
**Office of Health Strategy Consumer Consent Policy**  
**Recommendation**

**Section 1 Purpose**

Pursuant to Conn. Gen. Stat. § 17b-59a(c), the Office of Health Strategy “shall establish electronic data standards to facilitate the development of integrated electronic health information systems”. Conn. Gen. Stat. § 17b-59f further designates the Health Information Technology Advisory Council (HITAC) to advise the Office of Health Strategy (OHS) “in developing priorities and policy recommendations for advancing the state’s health information technology and health information exchange efforts and goals and to advise the executive director and officer in the development and implementation of the state-wide health information technology plan and standards and the State-wide Health Information Exchange, established pursuant to Conn. Gen. Stat. § 17b-59d. The advisory council shall also advise the executive director and officer regarding the development of appropriate governance, oversight and accountability measures to ensure success in achieving the state’s health information technology and exchange goals.”

This Policy represents the HITAC’s recommendations for the principles and standards that the Health Information Alliance, Inc. (HIA) should incorporate into the policies and procedures of the State’s health information exchange (HIE) regarding patient consent. These policies and procedures must include identification of key Federal, including but not limited to Health Insurance Portability and Accountability Act (HIPAA), and State law and regulations that govern access to or the release of Protected Health Information (PHI) and safeguards to ensure the security and proper use of patient PHI for the purposes set forth in Conn. Gen. Stat. § 17b-59d. The HIA should ensure that consumers are informed about the goals of the HIE, the benefits of participating in the HIE, and the member’s right to limit sharing of their PHI.

**Section 2 Scope**

(1) Policy Statement

- (a) The default consumer consent policy for the state’s HIE is opt-out. This means that a consumer must proactively, and explicitly, declare their desire not to permit their PHI to be included in the HIE. Opting out means that a consumer’s PHI may no longer be returned as the result of a query or sent as an encounter notification. Opting out does not affect or alter a provider’s use or disclosure of their patient’s PHI in Direct Messaging or other permitted uses and disclosures under applicable state and federal law.
- (b) With respect to sensitive and/or specially protected health information, the default consumer consent policy for the HIE is Affirmative Consent, as set forth in state or federal law, including but not limited to 42 C.F.R. Pt 2. This means that a provider may not disclose consumer sensitive and/or specially protected health information to or through the HIE without Affirmative Consent from the patient or the patient’s legally-authorized personal representative.

### Section 3 Opt-Out Process

- (1) The HIE shall not disclose a patient's PHI if the patient or the patient's legally-authorized personal representative has affirmatively elected to withdraw the default consent to their PHI being accessible via the HIE pursuant to the process set forth in this section. A consumer who affirmatively opts-out of participating in the HIE in the manner set forth herein will not have their PHI shared, returned as the result of a query or sent as an encounter notification.
- (2) The HIE is responsible for the maintenance of consumer consent preferences, enabling consumers to update their consent selections at will, and shall provide:
  - (a) a dedicated webpage for consumers to receive information about their consent options and processes,
  - (b) methods for consumers to make a consent decision including, but not limited to:
    - i. an online consent designation form,
    - ii. a toll-free telephone number, and
    - iii. a paper consent designation form.
  - (c) consumers with confirmation of their consent preference including, but not limited to:
    - i. the consumer's: name, date of birth, unique consumer identifier, as applicable;
    - ii. consent preference(s) and limitations to access;
    - iii. the date the consumer made the selection;
    - iv. expected date the selection will be active in the consumer's record in the HIE; and
    - v. a listing of available customer service and technical assistance contact options.
- (3) The HIE must process each request to modify a consumer's consent preference so that it is reflected in the HIE as soon as practicable.
- (4) Exceptions to Disclosure of PHI
  - (a) For patients participating in the HIE, the HIA may use and disclose a patient's PHI as permitted by applicable law and consistent with HIA policy. The consent selection principles and standards set forth in this Policy shall not apply to the following functions and activities:
    - i. Direct messaging, by which the health information exchange may transmit a patient's PHI from one participating provider to another participating provider involved in that patient's treatment;
    - ii. Reporting of PHI by the HIA for public health purposes and access to PHI by public health authorities;
    - iii. Access to or the disclosure or receipt of PHI for the proper management and administration of the HIE or to carry out the legal responsibilities of the HIE, including but not limited to performing system maintenance, testing, and troubleshooting and providing operational and technical support.; and
    - iv. Use and disclosure of PHI required by law.
- (5) Electronic Signatures
  - (a) Consumer signatures may be obtained electronically provided that there is an

electronic signature consistent with 15 U.S.C. § 7001 et seq., or any other applicable state or federal laws or regulations.

- (6) Durability
  - (a) A patient's opt-out preference selection and a patient's Affirmative Consent shall remain in effect unless and until consumer expressly changes the preference or Affirmative Consent in a manner defined in this Policy.
  
- (7) Revocability
  - (a) Consumers may opt-out of the HIE or revoke their affirmative consent at any time provided that such opt-out or revocation shall not preclude any provider that has received PHI via the HIE prior to such opt-out or revocation and incorporated such PHI into its records from retaining such information in its records, subject to applicable state and federal law.
  - (b) For consumers that chose to opt-out or revoke their affirmative consent, the HIA may retain the minimum necessary patient identifying information to identify the patient in the HIE for the sole purpose of capturing their consent choice.

#### **Section 4 Consumer Engagement**

- (a) The HIA should develop a consumer engagement plan and providers shall provide their patients with information concerning their consent options, including but not limited to:
  - i. a description of the processes established by the HIE;
  - ii. a statement in plain language explaining their consent options and consequences of opting-out; and
  - iii. staff support for consumer questions.
- (b) The HIA should ensure that its consumer engagement and outreach plan:
  - i. is promoted and distributed broadly throughout the state;
  - ii. easily accessible to all consumers, with accommodation and materials available in the top fifteen most prevalent languages spoken in the state; and
  - iii. accounts for health and social inequities and social determinants of health.
- (c) Consumers must be provided with information on where to file a complaint if they feel their PHI was used without their permission.

#### **Section 5 Use Cases**

- (a) HIA shall promote transparency with respect to proposed and implemented HIE use cases. In furtherance of such transparency, HIA shall seek ways to make use cases and related information accessible to the public, such as by posting information about use cases on HIA's public-facing website. HIA recognizes that a key principle of use case transparency is a thoughtful and accessible consent process.
- (b) As a fundamental element of HIA's design and development of any use case, the HIA shall evaluate the specific consent requirements and process for each use case and address the impact of applicable state and federal law on the proposed use case.