I. Purpose

California Health and Safety Code section 130290 was enacted in 2021 and establishes the creation of the California Health and Human Services Data Exchange Framework (“Data Exchange Framework”), which requires certain data sharing among Participants. The purpose of this policy is to set forth the responsibilities of Participants to enable the right of an Individual User or an Individual User’s Personal Representative to inspect and obtain a copy of PHI or PII about the Individual User in a timely manner.

II. Policy

To the extent permitted by Applicable Law, Participants shall provide an Individual User or the Individual User’s Personal Representative bidirectional access to the Individual User’s PHI or PII in accordance with this policy.

This policy shall be effective as of January 31, 2024.

III. Procedures

1. INDIVIDUAL USER ACCESS

   a. To the extent permitted by Applicable Law, an Individual User or an Individual User’s Personal Representative has a right of access to inspect and obtain a copy of PHI or PII about the Individual User, for as long as the PHI or PII is maintained by a Participant. Notwithstanding the foregoing, if permitted under Applicable Law, a Participant shall have the authority to deny right of access to inspect or obtain a copy of PHI or PII.

   b. Participants that maintain PHI or PII for an Individual User must respond to the Individual User’s or the Individual User’s Personal Representative’s request that self-reported Health and Social Services Information be added to the Individual User’s health records, and must have a process to correct inaccurate information and for reconciling discrepancies in such records to ensure accuracy.

   c. The Participant may require the Individual User or the Individual User’s Personal Representative to assert their right to access the Individual User’s PHI or PII in accordance with the HIPAA Regulations or other Applicable Law. Each Participant shall provide the Individual User or the Individual User’s Personal Representative with the option of using electronic means (e.g., email or secure web portal) or other such means as determined by the Governance Entity to assert their rights for Individual Access Services to PHI or PII.

2. INDIVIDUAL USE OR DISCLOSURE OF PHI OR PII

   a. Individual Users shall have the right to use or disclose their own PHI or PII, except for any limitations set forth by Applicable Law.
3. AUTHENTICATION

a. Prior to initiating Individual Access Services, the Participant shall be required to verify the identity of the Individual User or the Individual User’s Personal Representative using standards and methods consistent with 45 C.F.R. § 164.514(h) or other Applicable Law.

4. NO FEES FOR INDIVIDUAL ACCESS SERVICES

a. A Participant may not charge another Participant any fees for PHI or PII exchanged in furtherance of this section.

5. PROCESSING OF INDIVIDUAL ACCESS SERVICES REQUESTS

a. Participants shall process an Individual User or Individual User’s Personal Representative requests for Individual Access Services as follows:

   i. Each Participant that receives a request for Individual Access Services from an Individual User or an Individual User’s Personal Representative for whom it maintains PHI or PII shall provide such Individual User or Individual User’s Personal Representative with Individual Access Services in accordance with Cal. Health & Safety Code § 123100–123149.5 or other Applicable Law.

   ii. Unless otherwise prohibited by Applicable Law, if the Participant does not maintain the PHI or PII that is the subject of the request for access, and the Participant knows where the requested information is maintained, the Participant must inform the Individual User or Individual User’s Personal Representative where to direct the request for access.

   iii. With respect to a Participant query for Individual Access Services, the response shall be provided as required by these terms and conditions regardless of whether it was prompted by (a) the Individual User or (b) a Participant who provides Individual Access Services and has been selected by the Individual User who is requesting PHI or PII for Individual Access Services.

IV. Definitions

“Business Associate” shall mean an organization that is defined as a “business associate” in 45 C.F.R. § 160.103 of the HIPAA Regulations.

“Business Associate Agreement” shall mean a contract, agreement, or other arrangement that satisfies the requirements of 45 C.F.R. § 164.504(e), as applicable. With regard to Governmental Participants, a Business Associate Agreement may be a memorandum of understanding that satisfies the requirements of 45 C.F.R. § 164.504(e)(3).

“Individual Access Services” shall mean the services provided to satisfy the right of an Individual User or an Individual User’s Personal Representative to access and to obtain a copy of the Individual User’s PHI or PII under Applicable Law or to direct that it be sent to a third party consistent with 45 C.F.R. § 164.524 or any other Applicable Law or agreement.
All other capitalized terms not defined herein shall have the same meaning as set forth in the Data Sharing Agreement.

V. References

VI. Related Policies and Procedures

Permitted, Required and Prohibited Purposes Policy and Procedure

VII. Version History

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