

TITLE: Individual Rights	
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Program: Hawai'i HIE	Revision Date: June 19, 2019
Approved By: Hawai'i HIE Board of Directors	

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1. Purpose

HIPAA provides individuals with certain rights regarding their protected health information (PHI) accessed, used and disclosed via the Hawai'i HIE's Health eNet System ("Health eNet", the "System"). This policy describes such individual rights, and the roles of individuals, the Hawai'i HIE and Participants in allowing individuals to exercise those rights.

2. Scope

This policy applies to: 1) the Hawai'i HIE and all of its workforce members, 2) all Health eNet Authorized Users, 3) all Hawai'i HIE business associates, subcontractors, and 4) all Hawai'i HIE Participants.

This policy pertains to individuals whose PHI reside within the System, Participants that are covered entities as defined by HIPAA, and the Hawai'i HIE as a business associate of covered entity Participants.

3. Definitions

Personal Representative. A person, e.g. parent or guardian, agent acting for an individual under a power of attorney, with the authority to act on behalf of an individual, living or deceased, regarding decisions related to the individual’s health care and/or exercising the individual’s rights permitted by HIPAA with respect to the individual’s protected health information, per 45 CFR §164.502(g) and applicable state law.

Protected Health Information (PHI). Personally Identifiable Information related to the health care of an individual that meets the HIPAA definition at 45 CFR §160.103.

4. Policy

4.1. Individual Rights Regarding Protected Health Information. An individual, in accordance with HIPAA, other applicable federal and state laws, and guidance from the U.S. Office for Civil Rights¹, may submit requests to Participants and the Hawai’i HIE regarding PHI of the individual maintained in unique designated record sets, for the following:

- Restriction of the availability of the individual’s PHI via the Health eNet (including Opt-Out and Opt-Back-In, per sub-section 4.3, “Individual Participation in the Health eNet”, below)
- Access to the PHI
- Copies of the PHI
- Amendment of the PHI
- An accounting of disclosures of the PHI

4.2. Personal Representatives. Personal Representatives, in accordance with HIPAA, other applicable federal and state laws, and guidance from the U.S. Office for Civil Rights¹, may submit requests to Participants and the Hawai’i HIE to exercise the individual’s rights outlined in sub-section 4.1, “Individual rights Regarding Protected Health Information”, above.

A Participant may choose not to treat a person as the individual’s Personal Representative if the Participant reasonably believes that the Personal Representative might endanger the individual, e.g. in situations of domestic violence, abuse, or neglect.

Procedure
1. When making a request for an amendment to PHI, if an individual has a Personal Representative acting on his/her behalf, the Personal Representative will be required to provide proof of authority and/or identity to the Participant and/or the Hawai’i HIE.

4.3. Individual Participation in the Health eNet. Individuals have the right to request to Opt-Out (i.e. no longer allow their PHI to be available for query via the Health eNet Community Health Record [CHR]) and subsequently request to Opt-Back-In (i.e. revoke Opt-Out to allow their PHI to again be available for query) regarding their participation in the Health eNet.

¹ “Personal Representatives” guidance provided by the U.S. Office for Civil Rights:
<http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalreps.html>.

Procedure
1. The Hawai'i HIE, Participants, individuals (and their Personal Representatives) shall adhere to the Hawai'i HIE's HEN-009 <i>Individual Notice and Participation</i> Operational Policy and Procedure regarding Opt-Out and Opt-Back-In of an individual.

4.4. Requests for Access to and Copy of PHI of an Individual. The Hawai'i HIE will respond to an individual's request to access or obtain a copy of his/her medical record or designated record set maintained by the Hawai'i HIE in the Community Health Record (CHR), by referring the individual to the Participant. The Hawai'i HIE shall cooperate with the Participant in accordance with the terms of its Business Associate Agreement regarding such request. The Hawai'i HIE will not provide the individual with direct access to his/her records stored in the Health eNet.

The Hawai'i HIE shall charge a reasonable cost-based fee, based upon the Hawai'i HIE's labor costs needed to fulfill requests for copies of information provided on electronic media, or a cost-based fee for the production of hardcopies.

4.5. Requests for Amendment of PHI by an Individual

4.5.1. Amending Records of Contributing Participants. The Hawai'i HIE will respond to an individual's request for an amendment to his/her PHI by referring the individual to the Participant(s) that contributed the PHI. Only the Participant that contributed the PHI being amended may accept an amendment. A Participant that believes there is an error in the record of another Participant shall contact the other Participant to address the potential error.

The Participant shall determine whether to grant or deny an amendment request. If the Participant accepts the amendment, the Participant shall amend the record and, assisted by Hawai'i HIE, shall make reasonable efforts to determine other Participants that accessed or received such information through the Health eNet CHR. The Participant shall then be responsible to notify such other Participants of the amendment.

Procedure
1. Requester (i.e. individual or individual's Personal Representative) identifies need for amendment to the individual's PHI contributed by a Participant.
2. Requester contacts the Participant directly to request an amendment. (Skip to Step 5.)
3. A. Requester contacts the Hawai'i HIE requesting amendment to the individual's PHI contributed by a Participant, and includes the following information in the request: <ul style="list-style-type: none"> 1) Name of requester, 2) Relationship to, or authority to act on behalf of the individual (if the requester is a Personal Representative), 3) Name of individual to whom the requested amendment to PHI pertains (if different than requester), and

<p>4) Name of individual's provider that contributed the PHI to the Health eNet (i.e. provider must be a Hawai'i HIE Participant).</p> <p>B. The above information shall be submitted to the Hawai'i HIE via one of the following methods, to the attention of "Community Relations":</p> <p>1) Written request mailed to: 900 Fort Street Mall, Suite 1305 Honolulu, HI 96813; or</p> <p>2) Online form on the Hawai'i HIE's website.</p> <p>C. The Hawai'i HIE will forward requests for amendment received via other means, e.g. fax or e-mail, to the Participant.</p>
<p>4. Hawai'i HIE refers requester to the Participant that contributed the PHI to the Health eNet.</p>
<p>5. Participant shall determine whether or not to accept or deny the amendment request, based on Participant's policies and procedures. Participant shall notify the Hawai'i HIE of the final decision.</p>
<p>6. A. If Participant accepts the amendment request, the Participant shall contribute the amended information to the CHR, and notify the Hawai'i HIE that the amendment has been contributed.</p> <p>B. If Participant denies the amendment request, the Participant shall contribute the appended information, as required by 45 CFR 164.526, to the CHR, and notify the Hawai'i HIE that the appended information has been contributed.</p> <p>The Hawai'i HIE will then work with the Participant as necessary to ensure that the amended / appended information is accurate in the CHR.</p>
<p>7. If the amendment request has been accepted, Hawai'i HIE will assist the contributing Participant in identifying any other Participant(s) that have accessed the errant information. The contributing Participant shall then notify the other affected Participant(s) of the amendment.</p>

4.5.2. Amending Query Results in the Health eNet Community Health Record. If an individual contacts the Hawai'i HIE to request an amendment to his/her PHI within the Community Health Record (CHR), the Hawai'i HIE shall work with the individual and necessary Participants to grant or deny such request.

If a query error returned by the CHR record locator service RLS is due to an error in data contributed to the System, then the Hawai'i HIE shall deny the request, and follow the above provisions for Amending Records of Contributing Participants.

If a Participant directs Hawai'i HIE to make an amendment, the Hawaii HIE will use reasonable efforts to amend the RLS, and make reasonable efforts to determine which Participants accessed or retrieved the individual's records prior to the amendment. The Hawai'i HIE shall then be responsible to notify such Participants of the amendment.

Procedure
<p>1. A. Requester identifies need for amendment to the individual’s PHI within the Health eNet CHR, and includes the following information in the request for amendment to PHI within the CHR:</p> <ol style="list-style-type: none"> 1) Name of requester, 2) Relationship to, or authority to act on behalf of the individual (if the requester is a Personal Representative), 3) Name of individual to whom the requested amendment to PHI pertains (if different than requester). <p>B. The above information shall be submitted to the Hawai’i HIE via one of the following methods, to the attention of “Community Relations”:</p> <ol style="list-style-type: none"> 1) Written request mailed to: 900 Fort Street Mall, Suite 1305 Honolulu, HI 96813; or 2) Online form on the Hawai’i HIE’s website.
<p>2. Requester contacts the Participant directly to request an amendment. (Skip to Step 5.)</p>
<p>3. If a query error returned by the RLS is due to an error in data contributed to the System, then the Hawai’i HIE shall follow the above provisions for Amending Records of Contributing Participants.</p>
<p>4. If Hawai’i HIE accepts the amendment, Hawai’i HIE shall make reasonable efforts to determine which Participant(s) accessed or retrieved the individual’s records prior to the amendment.</p>
<p>5. Hawai’i HIE will amend the RLS as appropriate.</p>
<p>6. Hawai’i HIE will notify Participant(s) and requester of amendment within a timely manner in writing.</p>

4.6. Accounting of Disclosures. In response to any individual’s request for an accounting of disclosures of PHI, the Hawai’i HIE shall direct such a request to the data contributing Participant.

In response to a request from a Participant for an accounting of disclosures, the Hawai’i HIE shall provide the information necessary for that Participant to make this accounting.

Such accounting obligations shall survive termination of the business associate agreement between the Participant and the Hawai’i HIE, and shall continue as long as the Hawai’i HIE maintains PHI contributed by the Participant.

Procedure
<p>1. A request can be made for an accounting of disclosures made up to six (6) years prior to the request. The first request within a twelve (12) month period will be provided at no cost to the individual or Participant.</p>
<p>2. For subsequent accountings within a twelve (12) month period, the Hawai’i HIE shall charge a reasonable fee based upon the Hawai’i HIE’s labor costs in responding to a request for electronic information (or a cost-based fee for the production of non-</p>

electronic media copies), so long as the Hawai'i HIE informs the Participant and the Participant informs the individual in advance of the fee, and the individual is afforded an opportunity to withdraw or modify the request.

5. Revision History

Revision Date	Revision Type*	Author(s)	Revision Rationale, Description	Approved by
June 19, 2013	New	Legal/Policy Committee (policy sub-committee)	Initial version of policy	Hawai'i HIE Board of Directors
Feb 16, 2016	Amendment	Legal/Policy Committee	Table of contents, section numbering and procedures added; existing definitions and policy sections edited to reflect current Health eNet services and operations	Hawai'i HIE Board of Directors
June 19, 2019	Amendment	Legal/Policy Committee	Scheduled substantive review of operational policy; edited for conformity with applicable laws, standards, and guidance	Hawai'i HIE Board of Directors

* Revision Type options = New, Amendment, Minor Amendment, Consolidation (i.e. merging of multiple policies)