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Model Privacy Policies and Procedures for Health Information Exchange

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CONNECTING FOR HEALTH COMMON FRAMEWORK

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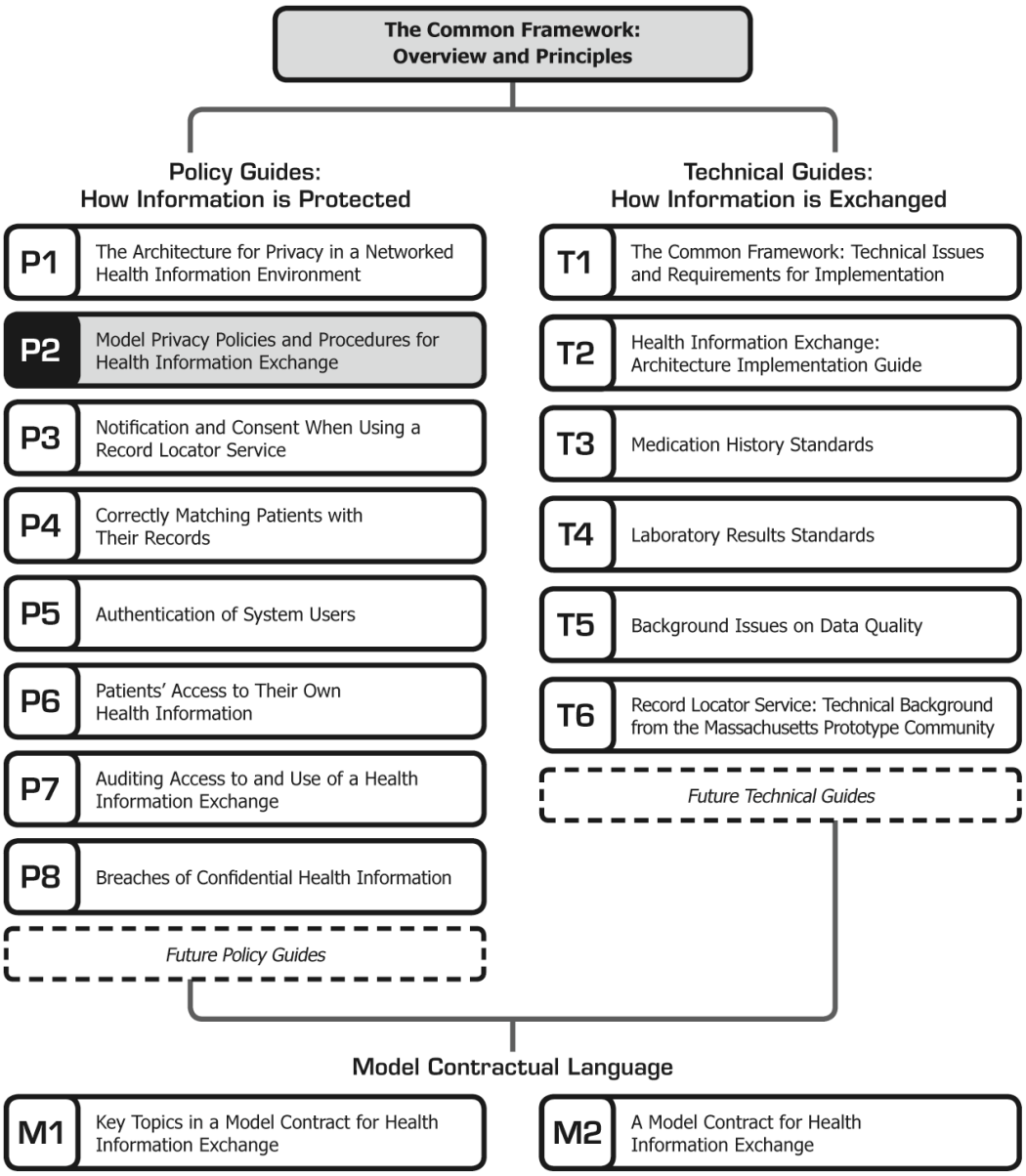

Model Privacy Policies and Procedures for Health Information Exchange*

The model policies contained in this paper are recommended by the **Connecting for Health** Policy Subcommittee to be used in conjunction with the **Connecting for Health** "Model Contract for Health Information Exchange"[1] for those working to establish sub-network organizations (SNOs)[2] that will use a Record Locator Service (RLS) and operate as part of the National Health Information Network (NHIN). The policies establish baseline privacy protections designed to apply to all individuals receiving care from a SNO Participant (Participant). The goal of these policies is to provide a framework for protecting health information while simultaneously permitting use of the information that is both productive and meaningful. The policies are intended to be useful for SNOs whether or not they are using an RLS**.**

The federal HIPAA Privacy and Security Rules provide the baseline for the model policies, although in some cases greater privacy protections and individual rights are recommended by the **Connecting for Health** Policy Subcommittee. Where provisions are derived from the HIPAA Privacy or Security Rules, citations are provided. In no instance do these policies permit less protection of personal health information than those required by federal law; however, participation in a SNO is not a surrogate for determining whether a Participant is a HIPAA "Covered Entity" or is in compliance with the HIPAA regulations. Importantly, the model policies permit Participants to establish and follow their own more protective data management, privacy and security policies, and procedures. In addition, some customization may be necessary at the SNO and Participant level to ensure consistency and compliance with applicable state laws. Many of these policies can and should already be in place at the Participant level. Some are aspirational and should be considered in the future as a networked environment for health information emerges and technology enables greater consumer access to their health records. The policies will need to be customized to reflect the Participants' unique circumstances and modified to take account of applicable state laws.

The model policies are deeply rooted in nine privacy principles that together form a comprehensive privacy protective architecture, as discussed in the **Connecting for Health** "Architecture for Privacy in a Networked Health Information Environment." These principles and the policies that flow from them promote balance between consumer control of and access to health information and the operational need to ensure that information uses and disclosures are not overly restricted such that consumers would be denied many of the benefits and improvements that information technology can bring to the health care system. The policies reflect a carefully balanced view of all of the principles and avoid emphasizing some over others in any way that would weaken the overall approach. The nine privacy principles are as follows:

Openness and Transparency. Openness about developments, procedures, policies, technology, and practices with respect to the treatment of personal health data is essential to

* **Connecting for Health** thanks Marcy Wilder of Hogan & Hartson LLP for drafting this paper.

1 See **Connecting for Health**, "A Model Contract for Health Information Exchange."

2 A sub-network organization (SNO) is to operate as a health information data exchange organization (whether regionally or affinity-based) that operates as a part of the National Health Information Network (NHIN), a nationwide environment for the electronic exchange of health information made up of a "network of networks."

protecting privacy. Individuals should be able to understand what information exists about them, how that information is used, and how they can exercise reasonable control over that information. This transparency helps promote privacy practices and instills confidence in individuals with regard to data privacy, which in turn can help increase participation in health data networks.

Purpose Specification and Minimization. Data use must be limited to the amount necessary to accomplish specified purposes. Minimization of use will help reduce privacy violations, which can easily occur when data is collected for one legitimate reason and then reused for different or unauthorized purposes.

Collection Limitation. Personal health data should be obtained only by fair and lawful means, and, if applicable, with the knowledge or consent of the pertinent individual. In an electronic networked environment, it is particularly important for individuals to understand how information concerning them is being collected because electronic collection methods may be confusing to average users. Similarly, individuals may not be aware of the potential abuses that can arise if they submit personal health information via an electronic method.

Use Limitation. The use and disclosure of health information should be limited to those purposes specified by the data recipient. Certain exceptions such as law enforcement or security may warrant reuse of data for other purposes. However, when data is used for purposes other than those originally specified, prior de-identification of the data can help protect individual privacy while enabling important benefits to be derived from the information.

Individual Participation and Control. Every individual should retain the right to request and receive in a timely and intelligible manner information regarding who has that individual's health data and what specific data the party has, to know any reason for a denial of such request, and to challenge or amend any personal information. Because individuals have a vital stake in their own personal health information, such rights enable them to be participants in the collection and use of their data. Individual participation promotes data quality, privacy, and confidence in privacy practices.

Data Integrity and Quality. Health data should be accurate, complete, relevant, and up-to-date to ensure its usefulness. The quality of health care depends on the existence of accurate health information. Moreover, individuals can be adversely affected by inaccurate health information in other arenas like insurance and employment. Thus, the integrity of health data must be maintained and individuals must be permitted to view information about them and amend such health information so that it is accurate and complete.

Security Safeguards and Controls. Security safeguards are essential to privacy protection because they help prevent data loss, corruption, unauthorized use, modification, and disclosure. With increasing levels of cyber-crime, networked environments may be particularly susceptible without adequate security controls. Design and implementation of various technical security precautions such as identity management tools, data scrubbing, hashing, auditing, authenticating, and other tools can strengthen information privacy.

Accountability and Oversight. Privacy protections have little weight if privacy violators are not held accountable for compliance failures. Employee training, privacy audits, and other oversight tools can help to identify and address privacy violations and security breaches by holding accountable those who violate

privacy requirements and identifying and correcting weaknesses in their security systems.

Remedies. The maintenance of privacy protection depends upon legal and financial means to remedy any privacy or security breaches. Such remedies should hold violators accountable for compliance failures, reassure individuals about the organization's commitment to information privacy, and mitigate any harm that privacy violations may cause individuals.

These nine principles underlie the recommended model privacy policies presented below. While certain principles are emphasized by each individual policy, the policies as a whole balance all of the principles equally so that certain principles are not emphasized over others—which would undermine the effectiveness of the overall approach. Moreover, the policies are individual elements of an integrated and comprehensive **Connecting for Health** policy framework—*The **Connecting for Health** Common Framework: Resources for Implementing Private and Secure Health Information Exchange*—that is intended to be considered in its entirety. In that regard, please refer to the following additional materials developed by the **Connecting for Health** Policy Subcommittee: "A Model Contract for Health Information Exchange," "Background Issues on Data Quality," "Auditing Access to and Use of a Health Information Exchange," "Breaches of Confidential Health Information," "Authentication of System Users," "Notification and Consent When Using a Record Locator Service," "Patients' Access to Their Own Health Information," and "Correctly Matching Patients with Their Records."

Although most of the recommended model policies can and should be implemented in the current technological environment, there are a few for which organizational and technical barriers may currently be prohibitive. For example, although patients would benefit from access to the RLS and the ability to obtain audit trails of those who have requested information about them from the index, technical and administrative barriers currently do not allow for such access. Health care participants, system vendors, and others should work toward implementing these functionalities as they will enhance privacy protections and help implement the privacy principles of openness and transparency, security safeguards and controls, purpose specification and minimization, use limitation, collection limitation, and accountability. Similarly, in the future, Participants and vendors should seek to realize the other policies that cannot be implemented at this time due to organizational and technical constraints.

The emergence of a networked electronic health information environment will transform patient care and improve the efficiency and effectiveness of the health system. At the same time, the emerging electronic health information infrastructure and the massive increase in the volume of health data that is easily collected, linked, and disseminated create unprecedented privacy and security risks that need to be adequately and appropriately addressed. By incorporating the principles outlined above and the basic requirements set forth in HIPAA, these recommended model policies seek to achieve a balance between maintaining the confidentiality of health information and maximizing the benefits of using such information. Integration of these privacy measures into the emerging networked health care environment can ensure that the benefits of electronic health information are realized while the confidentiality of health information is preserved.

Each of the recommended privacy policies outlined below contains an introductory section that provides background and explains the basis for the policy in law, the privacy principles described above, and other sources. The introductory sections are followed by recommended language for use by SNOs in drafting their own Policies and Procedures to use in conjunction with the **Connecting for Health** "Model Contract for Health Information Exchange."

SNO Policy 100: Compliance with Law and Policy

Purpose and Principles: In the spirit of the privacy principles of openness and transparency, data integrity and quality, accountability and

oversight, and remedies, a requirement that Participants comply with applicable law and SNO policies and promulgate the internal policies required for such compliance is indispensable to the successful realization of essential privacy protections. In addition, the recommended model provision below governing conflicts between SNO policies and Participant policies, which states that the policy that is most protective of individual privacy should govern decision making, is designed to make clear that the policies provide a floor and Participants may choose to enhance privacy protections where appropriate. This deference to more protective policies echoes the HIPAA federal pre-emption requirements which do not preempt more protective state privacy laws.[3]

The recommended policy's requirement that Participants develop internal policies will help implement the principles of sound data management practices and accountability as well as ensure that decisions affecting individuals' privacy interests are made thoughtfully, rather than on an ad hoc basis. Written documentation of such policies facilitates the training of personnel who will handle health information and enhances the accountability of both Participants and members of their workforce. Finally, the existence of internal policies for compliance with applicable law and SNO policies creates transparency surrounding Participants' handling and safeguarding of data. Policies to establish privacy protection compliance, enforcement procedures and remedies following violations are crucial to maintaining health information privacy.

Recommended Language

Scope and Applicability: This Policy applies to all Participants that have registered with and are participating in the SNO and the RLS and that may provide, make available, or request health information through the SNO and the RLS.

Policy:

1. **Laws.** Each Participant shall, at all times, comply with all applicable federal, state, and local laws and regulations, including, but not limited to, those protecting the confidentiality and security of individually identifiable health information and establishing certain individual privacy rights. Each Participant shall use reasonable efforts to stay abreast of any changes or updates to and interpretations of such laws and regulations to ensure compliance.

2. **SNO Policies.** Each Participant shall, at all times, comply with all applicable SNO policies and procedures ("SNO Policies"). These SNO Policies may be revised and updated from time to time upon reasonable written notice to Participant. Each Participant is responsible for ensuring it has, and is in compliance with, the most recent version of these SNO Policies.

3. **Participant Policies.** Each Participant is responsible for ensuring that it has the requisite, appropriate, and necessary internal policies for compliance with applicable laws and these SNO Policies. In the event of a conflict between these SNO Policies and an institution's own policies and procedures, the Participant shall comply with the policy that is more protective of individual privacy and security.

SNO Policy 200: Notice of Privacy Practices

Purpose and Principles: This recommended policy incorporates the HIPAA requirements obligating entities to provide individuals a notice of the entities' privacy practices.[4] The policy exceeds HIPAA's requirements by also requiring disclosures to individuals of certain information related to the SNO and RLS.[5] For example, under the model policy, the Privacy Notice should inform individuals about what information the Participant may make available

[3] 45 C.F.R. § 160.203.

[4] 45 C.F.R. § 164.520.

[5] HIPAA requires the Notice of Privacy Practices to include a description, with "at least one example, of the types of uses and disclosures that the covered entity is permitted … to make for … treatment, payment and health care operations" and a description of those other purposes for which the entity "is permitted or required … to use or disclose protected health information without" individual authorization. 45 C.F.R. § 164.520(b)(1)(ii)(A). Unlike this recommended model policy, HIPAA does not require the Privacy Notice to set forth what specific information may be disclosed and who may access the information.

through the SNO and RLS, who is able to access the information, and how they can have information concerning them removed from the RLS. These are not HIPAA requirements, but rather build and expand upon the privacy law to help incorporate information related to the NHIN and the RLS. This recommended model policy also exceeds HIPAA's requirements by providing suggestions for additional, voluntary protections that could be implemented on the Participant level to enhance consumer protections, such as excluding individuals from the RLS index unless prior consent is obtained or loading information into the RLS only after a notification and opportunity to decline participation has been provided to individual patients.

This recommended model policy promotes the privacy principles of openness and transparency, purpose specification and minimization, use limitation, collection limitation, and individual participation and control. In addition, the model policy helps ensure that information is collected and shared electronically in a fair manner with the knowledge of relevant individuals, which is particularly important in a networked environment where the technology may be unfamiliar to average users.

Recommended Language

Scope and Applicability: This Policy applies to all Participants that have registered with and are participating in the SNO and the RLS and that may provide or make available health information through the SNO and the RLS.

Policy:

Each Participant shall develop and maintain a notice of privacy practices (the "Notice") that complies with applicable law and this Policy.

1. **Content.** The Notice shall meet the content requirements set forth under the HIPAA Privacy Rule[6] and comply with all applicable laws and regulations. The Notice also shall include a description of the SNO and the RLS and inform individuals regarding: (1) what information the institution may include in and make available through the SNO and the RLS; (2) who is able to access the information in the SNO and the RLS; (3) for what purposes such information can be accessed; and (4) how the individual can have his or her information removed from the RLS.

2. **Provision to Individuals.** Each Participant shall have its own policies and procedures governing distribution of the Notice to individuals, which policies and procedures shall be consistent with this Policy and comply with applicable laws and regulations.

   - For Participants that are health care providers, the Notice shall be: (1) available to the public upon request; (2) posted on all web sites of the Participant and available electronically through such sites; (3) provided to a patient at the date of first service delivery; (4) available at the institution; and (5) posted in a clear and prominent location where it is reasonable to expect individuals seeking service to be able to read the Notice.[7]

   - For Participants that are health plans, the Notice shall be: (1) available to the public upon request; (2) provided to new enrollees at the time of plan enrollment; (3) provided to current plan enrollees within 60 days of a material revision; and (4) posted on the plan's web sites and available electronically through such sites. Participating health plan institutions also shall notify individuals covered by the plan of the availability of the Notice and how to obtain a copy at least once every three years.[8]

3. **Individual Acknowledgement.** Each Participant that is a health care provider shall make a good faith effort to obtain the individual's written acknowledgement of receipt of the Notice or to document their efforts and/or failure to do so. The acknowledgement of the Notice shall comply with all applicable laws and regulations.[9] Each Participant shall have its own policies and procedures governing obtaining an

[6] 45 C.F.R. § 164.520(b).

[7] See 45 C.F.R. § 164.520(c)(2), (3).

[8] See 45 C.F.R. § 164.520(c)(1), (3).

[9] See 45 C.F.R. § 164.520(c)(2)(ii).

acknowledgement, which policies and procedures shall be consistent with this Policy and comply with applicable laws and regulations.

4. **Participant Choice.** Participants may choose a more proactive notice distribution process than provided herein and may include more detail in their notice of privacy practices. Possible additional protections for individuals whose information may be made available through the RLS (not all of which pertain to notice policies alone) could include: mailing the revised notice or a notification letter allowing for removal or exclusion of the information about that individual from the RLS to every individual prior to loading the information into the RLS or shortly thereafter; excluding individuals from the RLS index unless individual consent is obtained; loading individual information into the RLS on a going-forward, new individual encounter basis only; developing a method for time-stamping an RLS record to indicate when the record was loaded into the index; developing a method for allowing individuals to limit access to their RLS records; and obtaining individual consent prior to each inquiry made to the RLS index by a Participant, or on a periodic basis.

SNO Policy 300: Individual Participation and Control of Information Posted to the RLS

Purpose and Principles: This recommended model policy provides greater privacy protection over personal health information than the HIPAA Privacy Rule by allowing individuals to elect whether or not to have information about them included in the RLS. Importantly, individuals are treated as participants in the process of health information collection and dissemination, rather than as spectators. Providing such consumer protections allows individuals to better understand the conditions under which information concerning them might be used, to restrict such use, and to develop confidence in the protections surrounding the use of their data.

This model policy promotes the privacy principles of individual participation and control, purpose specification and minimization, use limitation, and collection limitation. By enhancing reasonable individual control over the collection and use of health information the policy will promote consumer confidence that health information is being used and collected in accordance with individual preferences.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and the RLS and that may provide or make available health information through the SNO and the RLS.

Policy:

1. **Choice Not to Have Information Included in the RLS.** All individuals may choose not to have information about them included in or made available through the RLS.

2. **Effect of Choice.** An individual's choice not to have information about him or her included in or made available through the RLS shall be exercised through the Participant, as described in the institution's Notice, after which time the institution shall no longer include the individual in the RLS. Participants shall develop and implement appropriate mechanisms to remove information about an individual from the RLS if the individual chooses to have such information excluded from the RLS.

3. **Revocation.** An individual who has chosen not to make information concerning him or her available through the RLS subsequently may be included in the RLS only if the individual revokes his or her decision or subsequently chooses to renew participation in the RLS.

4. **Documentation.** Each Participant shall document and maintain documentation of all patients' decisions not to have information about them included in the RLS.

5. **Participant Choice.** Participants shall establish reasonable and appropriate processes to enable the exercise of a patient's choice not to have information

about him or her included in the RLS. Each Participant retains the authority to decide whether and when to obtain patient consent prior to making information available through the RLS.

6. **Provision of Coverage or Care.** A Participant shall not withhold coverage or care from an individual on the basis of that individual's choice not to have information about him or her included in the RLS.

SNO Policy 400: Uses and Disclosures of Health Information

Purpose and Principles: Through a variety of mechanisms, this model policy reflects the privacy principles of purpose specification and minimization, security safeguards and controls, use limitation, collection limitation, accountability and oversight, and data integrity and quality. The recommended policy integrates HIPAA's general premise that health information may be used only for permissible purposes and its more specific requirement that entities may disclose only the amount of information reasonably necessary to achieve a particular purpose.[10] In general, requests for disclosure of and/or use of health information for treatment, payment, and the health care operations of a covered entity, as each is defined by HIPAA, will be permitted.[11] Furthermore, subject to certain limitations and under certain circumstances, requesting disclosure of and using health information for law enforcement,[12] disaster relief,[13] research,[14] and public health[15] purposes also may be permissible. Accessing health information through either the RLS or the SNO for marketing or marketing-related purposes is prohibited without specific patient authorization.[16] Under no circumstances may health information be accessed or used for discriminatory purposes. For example, a health plan would not be permitted to use the RLS to determine if a member has visited a health care provider for whom the health plan has not been billed. Such activity would be an impermissible and discriminatory purpose and is prohibited by applicable law and under this Policy. SNOs may provide guidance to Participants detailing the permissibility or impermissibility of requesting or using health information for certain specified purposes under applicable law.

Requiring consideration of the purpose of a use and minimization of the use of information reduces the likelihood of inadvertent or intentional misuses of information. The model policy helps enhance the fair and legal collection and use of data, the oversight of data use and accountability for privacy violations by ensuring that Participants have legally required documentation prior to the use or disclosure of information.[17] In addition, the integration of HIPAA's accounting of disclosures and individual access to information requirements allows individuals to understand how health information about them is shared and to exercise certain rights regarding information about them with greater precision and ease.[18]

The recommended provision also requires security measures essential to identify and remedy loss, unauthorized access, destruction, use, modification, or disclosure of personal health information. The audit requirement reflects the HIPAA Security Rule's general

[10] 45 C.F.R. § 164.502(b).

[11] 45 C.F.R. §§ 164.502(1)(ii), 506. Under HIPAA, treatment is defined as "the provision, coordination, or management of health care and related services by one or more health care providers … " 45 C.F.R. § 164.501. Payment refers to "activities undertaken by: (i) A health plan to obtain premiums or to determine or fulfill its responsibility for coverage and provision of benefits under the health plan; or (ii) A covered health care provider or health plan to obtain or provide reimbursement for the provision of health care." Such activities include eligibility and coverage determinations; risk adjustments; billing, claims management and collection activities; medical necessity review; and utilization review. Id. Health care operations includes activities related to covered functions for (i) conducting quality assessment and improvement; (ii) evaluating competence, qualifications and performance of health care professionals, evaluating health plan performance, training and credentialing activities; (iii) underwriting, "premium rating, and other activities relating to the creation, renewal or replacement of a contract of health insurance or health benefits"; (iv) "conducting or arranging for medical review, legal services, and auditing functions;" (v) business planning and development; and (vi) business management and administrative activities. Id.

[12] 45 C.F.R. § 164.512(f).

[13] 45 C.F.R. § 164.510(b)(4).

[14] 45 C.F.R. § 164.512(i).

[15] 45 C.F.R. § 164.512(b).

[16] 45 C.F.R. 164.508(a)(3) & (b).

[17] See 45 C.F.R. § 164.530(j).

[18] See 45 C.F.R. §§ 164.528; 164.524.

requirement that entities implement policies to prevent security violations, assess security risks, and examine data storage and access technology[19] but, in a manner more protective than HIPAA, would establish monitoring requirements as to when information is accessed and by whom. To prevent unauthorized access of information and maintain data integrity and quality the authentication provision of the model policy requires that both the identity and authority of an entity requesting health information be verified and authenticated, integrating requirements from the HIPAA Privacy Rule and Security Rule.[20]

The combination of this recommended policy's use and security provisions helps guarantee that health information is used and accessed only as authorized and that Participants have proper measures in place to identify and address privacy violations. Consequently, individuals can remain confident that information about them is being used with care and in the manner promised by Participants.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide, make available, or request health information through the SNO.

Policy:

1. **Compliance with Law.** All disclosures of health information through the SNO and the use of information obtained from the SNO shall be consistent with all applicable federal, state, and local laws and regulations and shall not be used for any unlawful discriminatory purpose. If applicable law requires that certain documentation exist or that other conditions be met prior to using or disclosing health information for a particular purpose, the requesting institution shall ensure that it has obtained the required documentation or met the requisite conditions and shall provide evidence of such at the request of the disclosing institution.[21]

2. **Purposes.** A Participant may request health information through the RLS or SNO only for purposes permitted by applicable law. Each Participant shall provide or request health information through the RLS or SNO only to the extent necessary and only for those purposes that are permitted by applicable federal, state, and local laws and regulations and these Policies.[22] Information may not be requested for marketing or marketing related purposes without specific patient authorization. Under no circumstances may information be requested for a discriminatory purpose. In the absence of a permissible purpose, a Participant may not request information through the RLS or from the SNO.

3. **SNO Policies.** Uses and disclosures of and requests for health information via the SNO shall comply with all SNO Policies, including, but not limited to, the SNO Policy on Minimum Necessary and the SNO Policy on Information Subject to Special Protection.[23]

4. **Participant Policies.** Each Participant shall refer to and comply with its own internal policies and procedures regarding disclosures of health information and the conditions that shall be met and documentation that shall be obtained, if any, prior to making such disclosures.

5. **Accounting of Disclosures.** Each Participant disclosing health information through the SNO shall work towards implementing a system to document the purposes for which such disclosures are made, as provided by the requesting institution, and any other information that may be necessary for compliance with the HIPAA Privacy Rule's accounting of disclosures requirement.[24] Each Participant is responsible for ensuring its compliance with such requirement and may choose to

[19] 45 C.F.R. §§ 164.316, 164.308(a)(1)(i).
[20] 45 C.F.R. §§ 164.514(h), 164.312(d).
[21] See 45 C.F.R. § 164.530(j).
[22] 45 C.F.R. § 164.502(a), (b).
[23] 45 C.F.R. § 164.502(b).
[24] 45 C.F.R. § 164.528. For HIPAA Covered Entities, this is currently required by law.

provide individuals with more information in the accounting than is required. Each requesting institution shall provide information required for the disclosing institution to meet its obligations under the HIPAA Privacy Rule's accounting of disclosures requirement.

6. **Audit Logs.** Participants and SNOs shall consider and work towards maintaining an audit log documenting which Participants posted and accessed the information about an individual through the RLS and when such information was posted and accessed.[25] Participants and SNOs shall consider and work towards implementing a system wherein, upon request, patients have a means of seeing who has posted and who has accessed information about them through the RLS and when such information was accessed.[26]

7. **Authentication.** Each Participant shall follow uniform minimum authentication requirements for verifying and authenticating those within their institutions who shall have access to, as well as other Participants who request access to, information through the SNO and/or the RLS.[27] [28]

8. **Access.** Each SNO should have a formal process through which information in the RLS can be requested by a patient or on a patient's behalf.[29] Participants and SNOs shall consider and work towards providing patients direct access to the information contained in the RLS that is about them.[30]

SNO Policy 500: Information Subject to Special Protection

Purpose and Principles: This model policy promotes the privacy principles of purpose specification and minimization, security safeguards and controls, use limitation, data integrity and quality, collection limitation, and individual participation and control. This recommended provision facilitates individualized privacy protections by requiring Participants to heed any special protections of certain information set forth under applicable law. In complying with these special protections, Participants' collection, use and disclosure of health information is limited to legitimate purposes. Moreover, in guaranteeing deference to the law or policy most protective of privacy, the provision below echoes HIPAA's federal preemption requirements which defer to state laws that are more protective than HIPAA's own privacy provisions.[31]

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide or make available health information through the SNO.

Policy:

Some health information may be subject to special protection under federal, state, and/or local laws and regulations (e.g., substance abuse, mental health, and HIV). Each Participant shall determine and identify what information is subject to special protection under applicable law prior to disclosing any information through the SNO. Each Participant is responsible for complying with such laws and regulations.

SNO Policy 600: Minimum Necessary

Purpose and Principles: To promote the privacy principles of collection limitation, use limitation, data integrity and quality, and security safeguards and controls, this recommended model policy incorporates HIPAA's requirement that entities may disclose only the amount of information reasonably necessary to achieve a particular purpose.[32] The policy exempts treatment disclosures from this minimum necessary requirement to balance the protection of privacy and the provision of quality

[25] See 45 C.F.R. §§ 164.316, 164.308(a)(1)(i).
[26] See **Connecting for Health**, "Auditing Access to and Use of a Health Information Exchange."
[27] See 45 C.F.R. §§ 164.514(h), 164.312(d).
[28] See **Connecting for Health**, "Authentication of System Users."
[29] See 45 C.F.R. § 164.524.
[30] See **Connecting for Health**, "Patients' Access to Their Own Health Information."
[31] 45 C.F.R. § 164.203.
[32] 45 C.F.R. § 164.502(b).

health care. In assessing the smallest amount of information that is necessary to accomplish a particular purpose, Participants are less likely to collect, use or disclose information for an unauthorized purpose. Minimal collection, access, use and disclosure increases public confidence in the privacy practices of Participants, enhances information privacy, and diminishes the potential for data corruption and security violations.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide, make available, or request health information through the SNO.

Policy:

1. **Uses.** Each Participant shall use only the minimum amount of health information obtained through the SNO as is necessary for the purpose of such use. Each Participant shall share health information obtained through the SNO with and allow access to such information by only those workforce members, agents, and contractors who need the information in connection with their job function or duties.

2. **Disclosures.** Each Participant shall disclose through the SNO only the minimum amount of health information as is necessary for the purpose of the disclosure. Disclosures to a health care provider for treatment purposes and disclosures required by law are not subject to this Minimum Necessary Policy.

3. **Requests.** Each Participant shall request only the minimum amount of health information through the SNO as is necessary for the intended purpose of the request. This Minimum Necessary Policy does not apply to requests by health care providers for treatment purposes.

4. **Entire Medical Record.** A Participant shall not use, disclose, or request an individual's entire medical record except where specifically justified as the amount that is reasonably necessary to accomplish the purpose of the use, disclosure, or request. This limit does not apply to disclosures to or requests by a health care provider for treatment purposes or disclosures required by law.

SNO Policy 700: Workforce, Agents, and Contractors

Purpose and Principles: By incorporating HIPAA's administrative requirements for workforce training, sanctions for privacy violations, and the reporting of complaints,[33] this recommended model policy advances the privacy principles of use limitation, security safeguards and controls, accountability and oversight, data integrity and quality, and remedies. Because a Participant's workforce is responsible for implementation of privacy practices, proper training is vital to ensure the legitimate use of health information and the prompt identification, reporting, and correction of any security weaknesses. Individual accountability in the form of sanctions for those persons responsible for privacy violations is fundamental to encouraging compliance with privacy practices. Without such incentive for compliance, privacy violations and security risks may go unchecked and lead to larger privacy problems. Similarly, providing for the reporting of non-compliance enables Participants to discover and correct privacy violations and identify and sanction privacy violators. This model policy helps guarantee the legitimate use of health data, the proper implementation of Participants' privacy practices, and the prompt identification of and undertaking of remedial action for privacy violations.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide, make available, or request health information through the SNO.

Policy:

1. **Access to System.** Each Participant shall allow access to the SNO only by those workforce members, agents, and contractors who have a legitimate and appropriate need to use the SNO and/or

[33] 45 C.F.R. § 164.530.

release or obtain information through the SNO. No workforce member, agent, or contractor shall be provided with access to the SNO without first having been trained on these Policies, as set forth below.

2. **Training.** Each Participant shall develop and implement a training program for its workforce members, agents, and contractors who will have access to the SNO to ensure compliance with these Policies.[34] The training shall include a detailed review of applicable Policies and each trained workforce member, agent, and contractor shall sign a representation that he or she received, read, and understands these Policies.

3. **Discipline for Non-Compliance.** Each Participant shall implement procedures to discipline and hold workforce members, agents, and contractors accountable for ensuring that they do not use, disclose, or request health information except as permitted by these Policies and that they comply with these Policies.[35] Such discipline measures shall include, but not be limited to, verbal and written warnings, demotion, and termination and provide for retraining where appropriate.

4. **Reporting of Non-Compliance.** Each Participant shall have a mechanism for, and shall encourage, all workforce members, agents, and contractors to report any non-compliance with these Policies to the Participant.[36] Each Participant also shall establish a process for individuals whose health information is included in the RLS to report any non-compliance with these Policies or concerns about improper disclosures of information about them.

SNO Policy 800: Amendment of Data

Purpose and Principles: This recommended model policy integrates the right granted by the HIPAA Privacy Rule of individuals to amend health information about them under certain circumstances.[37] Accurate health information not only is indispensable to the delivery of health care, but is important to individuals' applications for insurance and employment and in a variety of other arenas. Allowing individuals to verify the accuracy and completeness of information concerning them contributes to the transparency of Participants' operations and fosters confidence in Participants' privacy practices and commitment to data accuracy. This policy promotes the privacy principles of data integrity and quality, openness and transparency, individual participation and control, and accountability and oversight. Using such a model policy will enable Participants to more readily rely upon the integrity and quality of their data and more easily monitor, account for, and remedy systemic data inaccuracies, corruptions, and other data deficiencies or privacy lapses.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide, make available, or request health information through the SNO.

Policy:

Each Participant shall comply with applicable federal, state and local laws and regulations regarding individual rights to request amendment of health information.[38] If an individual requests, and the Participant accepts, an amendment to the health information about the individual, the Participant shall make reasonable efforts to inform other Participants that accessed or received such information through the SNO, within a reasonable time, if the recipient institution may have relied or could foreseeably rely on the information to the detriment of the individual.

SNO Policy 900: Requests for Restrictions

Purpose and Principles: To advance the privacy principles of individual participation and control, use limitation and accountability and oversight, this recommended model policy

[34] *See* 45 C.F.R. § 164.530(b).
[35] 45 C.F.R. § 164.530(e).
[36] *See* 45 C.F.R. § 164.530(a), (d).
[37] 45 C.F.R. § 164.526.
[38] 45 C.F.R. § 164.526.

requires Participants who agree to individuals' request for restrictions in accordance with the HIPAA Privacy Rule to comply with such request with regard to the release of information in the SNO.[39] Such compliance ensures permissible use of health information and accountability on the part of Participants who agree to individually requested use restrictions. Without the ability to request restrictions and without assurance that Participants will honor these agreed-upon restrictions, individuals may remain silent about important information that could affect their health. By creating confidence in Participants and their privacy protections and encouraging individual participation, this policy fosters dialog between individuals and Participants. Improved communications between a provider and patient improves the overall delivery of health care.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide or make available health information through the SNO.

Policy:

If a Participant agrees to an individual's request for restrictions,[40] as permitted under the HIPAA Privacy Rule, such Participant shall ensure that it complies with the restrictions when releasing information through the SNO. If an agreed-upon restriction will or could affect the requesting institution's uses and/or disclosures of health information, at the time of disclosure, the Participant disclosing such health information shall notify the requesting institution of the fact that certain information has been restricted, without disclosing the content of any such restriction.

[39] 45 C.F.R. § 164.522.

[40] Under the HIPAA Privacy Rule, individuals have the right to request restrictions on the use and/or disclosure of health information about them. 45 C.F.R. § 164.522. For example, an individual could request that information not be used or disclosed for a particular purpose or that certain information not be disclosed to a particular individual. Covered entities are not required to agree to such requests under HIPAA.

SNO Policy 1000: Mitigation

Purpose and Principles: By incorporating HIPAA's requirement that entities have procedures to and take steps to mitigate harm resulting from an impermissible use or disclosure of health information,[41] this model policy reflects the privacy principles of remedies, accountability and oversight, security safeguards and controls, openness and transparency, and data integrity and quality. Without the duty to mitigate harm from privacy violations, Participants may not promptly address data security weaknesses or breaches which could lead to greater privacy lapses in the future, diminish the confidence that individuals have in Participants' privacy practices, and compromise the accuracy, integrity, and quality of Participants' data. Remedial action and mitigation are essential both to reassure individuals that Participants are vigilant in addressing privacy violations and ameliorating any harm from such violations and to help Participants ensure that their data oversight practices and security measures are functioning and effective.

Recommended Language

Scope and Applicability: This Policy applies to all institutions that have registered with and are participating in the SNO and that may provide, make available, or request health information through the SNO.

Policy:

Each Participant shall implement a process to mitigate, and shall mitigate and take appropriate remedial action, to the extent practicable, any harmful effect that is known to the institution of a use or disclosure of health information through the SNO in violation of applicable laws and/or regulations and/or these Policies by the institution, or its workforce members, agents, and contractors. Steps to mitigate could include, among other things, Participant notification to the individual of the disclosure of information about them or Participant request to the party who received such information to return and/or destroy the impermissibly disclosed information.

[41] 45 C.F.R. § 164.530(f).

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