

Introduction

Effective as of July 10, 2024, New York State has published regulations (the SHIN-NY Regulations) requiring that the New York State Department of Health (the Department) “provide, either directly or through contract, [the Statewide Data Infrastructure (the SDI)] and any other SHIN-NY services that the [the Department] deems necessary to effectuate the purposes of [the SHIN-NY Regulations].”¹ The SDI, which includes a secure statewide data repository as well as centralized systems operated or directed by New York eHealth Collaborative (NYeC), will support increased interoperability, provide flexibility for the SHIN-NY to adapt in a constantly evolving technological environment, and facilitate the exchange of data among SHIN-NY participants, including the Department.

SHIN-NY participants that have received a waiver from the Department under 10 N.Y.C.R.R. § 300.6(b)(4) will connect to the SDI, ensure that patient data is contributed to the SDI and authorize the use of patient data for statewide reporting and analytics for public health surveillance and Medicaid purposes, in accordance with the SHIN-NY SOPs.

NYeC, as the State Designated Entity (SDE) for the SHIN-NY, will maintain the technical and administrative resources which comprise the SDI. The Statewide Data Use Committee (SDUC), a standing committee of the SHIN-NY statewide collaboration process (SCP), will provide stakeholder engagement and governance support for the SDI. In these roles, NYeC and the SDUC will administer requests for use of SDI Data (as defined below), manage the provision of SDI Data to Authorized Requesters, and uphold a transparent and open governance model for data use, in each case in accordance with and pursuant to this SOP.

SOP Purpose, Scope, Limitations, and Audience

Purpose

This SOP explains the requirements and procedures for the use, disclosure, and re-disclosure of SDI Data. This includes the disclosure to the Department and the use and re-disclosure of SDI Data to support statewide reporting and analytics for public health activities and Medicaid purposes. The SOP also establishes procedures to ensure that SDI Data is only used, disclosed and re-disclosed only for the SDI Permitted Purposes (as defined below).

Scope

This SOP details the requirements and procedures for the use, disclosure, and re-disclosure of

¹ 10 N.Y.C.R.R. § 300.2(c).



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SDI Data for the Public Health Permitted Purposes and Medicaid Permitted Purposes. It also allows SDI Data to be used for other approved SDI Permitted Purposes that may be identified over time, subject to the limitations described below.

All actions of the Statewide Data Use Committee (SDUC) described here (including without limitation any approval or denial of any Data Use Request) shall be exercised in accordance with the SDUC Charter.

Limitations

This SOP does not apply to: (1) the use, disclosure, or re-disclosure of SDI Data for Treatment and Care Management Purposes; (2) the use, disclosure, or redisclosure of SDI Data, as permitted by the SHIN-NY Privacy and Security SOP², where data is supplied to or accessed by QEs or NYeC from the SHIN-NY Primary Document Repository (PDR) for disclosure to SHIN-NY participants, other than state or federal government participants; and (3) SDI Permitted Purposes that are required to maintain and operate the SHIN-NY. Accordingly, no additional SDUC approval is required for the following uses:

- Treatment and Care Management Purposes under circumstances where data is supplied to or accessed by QEs or NYeC for disclosure to SHIN-NY participants for Treatment or Care Management as permitted by the Statewide Common Participation Agreement (SCPA) and applicable SHIN-NY SOPs;
- Purposes permitted by the SHIN-NY Privacy and Security SOP (including but not limited to the following: organ procurement organization access, disclosures to payer organizations for quality measures, disclosures to death investigators, research) where data is supplied to or accessed by QEs or NYeC from the PDR for disclosure to SHIN-NY participants, other than state or federal government participants. Disclosure for such purposes to SHIN-NY participants other than state or federal government participants shall be subject to the requirements of the SHIN-NY Privacy and Security SOP and the SHIN-NY PDR Access SOP.
- Maintaining and operating the Statewide Master Patient Index (sMPI) and the Statewide Patient Record Lookup (sPRL);
- Facilitating the exchange of data within the SHIN-NY;
- Facilitating the tracking, monitoring, and exchange of data related to patient consents, including without limitation, maintaining and operating a statewide consent management system; and
- Operating the SDI, including but not limited to:
 - (A) collecting, aggregating, and performing quality assurance on data

² See “Exceptions to Affirmative Consent Requirement” in the SHIN-NY Privacy and Security SOP.



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- contributed to, held, maintained in, or transmitted through the SDI;
- (B) conducting inquiries and performing discovery with respect to Core SDI Data (as defined in the SCPA) to assess the scope of Core SDI Data and/or whether it is feasible to fulfill a potential data use request; and
- (C) analyzing Core SDI Data to assess the feasibility of developing new Required Participant Services (as defined in the SCPA) or other types of services to be provided through the SHIN-NY.
- This SOP does not apply to the use, disclosure or re-disclosure of data from QE Platforms, unless such data has been obtained from the SDI. In those cases, the use, disclosure or re-disclosure of such data for the QE Permitted Purpose of Public Health requires SDUC approval as described in this SOP.
- Additional SOP(s) may be developed in accordance with the Statewide Collaboration Process to address the use, disclosure and re-disclosure of QE Platforms data for other QE Permitted Purposes (as defined in the SCPA) aside from Public Health.
- This SOP applies to data that is originally maintained in QE Platforms but later contributed, shared, disclosed, transferred or otherwise made available to the SDI, including as described in the definition of SDI Data.

Audience

The audience for this SOP includes QEs, required and voluntary SHIN-NY participants, New York State and local public health authorities, health care consumers, and all other stakeholders with an interest in the SHIN-NY and the SDI.

Definitions

Authorized Requester means designated staff of QEs, NYeC, or the Department and designated staff of such other entities as may be approved by the SDUC.

Care Management has the meaning set forth in the SHIN-NY Privacy and Security SOPs. As of the date hereof, Care Management is defined to mean (i) assisting a patient in obtaining appropriate medical care, (ii) improving the quality of health care services provided to a patient, (iii) coordinating the provision of multiple health care services to a patient, (iv) supporting a patient in following a plan of medical care, or (v) assisting a patient in obtaining social services or providing social services to a patient.

Care Management Purposes are those related to Care Management as permitted under the SCPA and applicable SHIN-NY SOPs.

Data Lake means a secure data repository that is part of the SDI.



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Data Use and Contribution Agreement (DUCA) means the agreement between a QE and NYeC regarding such QE's contribution of data to the Data Lake and QE's and NYeC's use and disclosure of such data.

Data Use Requests means requests for use, disclosure and re-disclosure of Core SDI Data for Public Health Permitted Purposes, Medicaid Permitted Purposes, as well as any future SDI Permitted Purposes that the SDUC may review and approve. Each Data Use Request shall include a detailed explanation of the intended use, disclosure or re-disclosure of Core SDI Data, and the basis on which the intended use, disclosure or re-disclosure is for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations). For the avoidance of doubt, Data Use Requests may apply to multiple conditions or diseases. For instance, a Data Use Request may seek access to hospital admissions involving communicable diseases, which could apply to different communicable diseases. All Data Use Requests shall be produced in a standard format using the form included as Attachment A to this SOP as a guide. The form of Attachment A may be updated by NYeC from time to time to facilitate operationalization, intake, or processing of Data Use Requests; to conform to changes in applicable laws, regulations, the SCPA, SHIN-NY SOPs, and/or other similar governing documents; or to make other modifications as NYeC, in its sole discretion, deems necessary and appropriate. All such updates must be consistent with this SOP.

De-identified Data has the meaning set forth in the SHIN-NY Privacy and Security SOPs. As of the date hereof, De-identified Data is defined as data that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual. Data may be considered de-identified only if it satisfies the requirements of 45 C.F.R. § 164.514(b).

Limited Data Set (LDS) has the meaning set forth in the Privacy and Security SHIN-NY SOPs. As of the date hereof, Limited Data Set is defined as Protected Health Information (as defined therein) that excludes the 16 direct identifiers set forth at 45 C.F.R. § 164.514(e)(2) of an individual and the relatives, employers or household members of such individual.

Narrow Data Use Request means a Data Use Request for data consisting solely of a Limited Data Set, De-Identified Data, and/or aggregate data (*i.e.*, non-individual level statistics). For example, a Data Use Request for a de-identified flat file containing all calendar year 2023 patient encounters in New York State with CPT code 33418, for patients who live in New York State, including patient's county of residence only, is a Narrow Data Use Request. The SDUC may establish additional criteria that must be satisfied in order to constitute a Narrow Data Use Request.



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Material Change to Approved Data Use Request means a modification that would alter the nature and/or scope of an Approved Data Use Request as follows: (1) a modification that would alter the scope of the SDI Permitted Purpose(s) or the intended use(s) for which the SDI Data was approved to be used, disclosed, or re-disclosed; (2) a modification that would provide access to additional SDI Data element(s); (3) a modification that would change the type of data requested (i.e., identified, limited data set or de-identified). For all proposed Material Changes to Approved Data Use Requests, the requester must submit a new Data Use Request for review and approval in accordance with this SOP.

Medicaid Permitted Purposes means “purposes related to the administration of the Medicaid program, including but not limited to reporting to support any Social Security Act section 1115 waiver approved by the Centers for Medicare and Medicaid Services.”³

Modification of Approved Data Use Request means a change to an Approved Data Use Request that is not Material and that is initiated by NYeC or an Authorized Requestor and implemented by NYeC upon a determination by NYeC, in its sole discretion, that such change is not a Material Change to an Approved Data Use Request (as defined above). Examples of changes that are not Material may include, but are not limited to, administrative, operational, and clarifying updates such as correcting typographical errors, updating points of contact, updating frequency of data disclosure, or clarifying narrative descriptions that do not alter the scope of the Approved Data Use Request.

Primary Document Repository (PDR) means the centralized, statewide clinical document store within the SDI that contains Continuity of Care Documents (CCDs), discharge summaries, and other structured clinical documents contributed by SHIN-NY participants. Data in the PDR is accessible by NYeC and the QEs for SDI Permitted Purposes.

Public Health Permitted Purposes means “purposes for which a SHIN-NY participant is permitted to disclose protected health information to a public health authority without an authorization or opportunity to agree or object under federal standards for uses and disclosures for public health activities,”⁴ which purposes are further defined in the Privacy and Security SHIN-NY SOPs.

QE Platform means the platform by which a QE maintains data contributed, shared, disclosed transferred or otherwise made available by SHIN-NY participants in accordance with the SCPA.

Qualified Entity Participation Agreement (QEPA) means the agreement or set of agreements between NYeC and each QE pursuant to which such QE participates in the SHIN-NY, as such

³ 10 N.Y.C.R.R. § 300.1(p).

⁴ 10 N.Y.C.R.R. § 300.1(o).



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agreements may be amended, modified or replaced from time to time.

SDI Data means all data maintained in the SDI. SDI data includes, but is not limited to, any data contributed, shared, disclosed, transferred or otherwise made available to NYeC by SHIN-NY participants or the Department pursuant to and in accordance with the SCPA, by QEs pursuant to the QEPA, or by the Department pursuant to a Data Use Agreement (DUA). SDI Data also includes data contributed, shared, disclosed, transferred or otherwise made available to NYeC by QEs or SHIN-NY participants, where applicable, specifically in fulfillment of a Data Use Request approved pursuant to this SHIN-NY SOP (except as set forth in the “Limitations” section of this SOP), whether contributed, shared, disclosed, transferred or otherwise made available to NYeC before or after such approval (e.g., upon approval of a Data Use Request and in order to operationalize such approved Data Use Request, NYeC may request from QEs certain data maintained in the QE Platforms. QEs shall provide such data to NYeC pursuant to and in accordance with the QEPA, at which point such data shall become SDI Data and may be shared subject to and in accordance with such approved Data Use Request).

SDI Permitted Purposes means the purposes for which SDI Data may be used or disclosed by NYeC and QEs. The SDI Permitted Purposes shall include, at a minimum:

1. Public Health Permitted Purposes;
2. Medicaid Permitted Purposes;
3. Maintaining and operating the “Statewide Master Patient Index” and the “Statewide Patient Record Lookup” each as defined by or described in the SHIN-NY SOPs;
4. Treatment and Care Management Purposes under circumstances where data is supplied to or accessed by QEs or NYeC for disclosure to SHIN-NY participants for Treatment or Care Management as permitted by the SCPA and applicable SHIN-NY SOPs;
5. Facilitating the tracking, monitoring, and exchange of data related to patient consents, including without limitation maintaining and operating a statewide consent management system;
6. Fulfilling NYeC’s obligations related to the SHIN-NY and the SCPA, including but not limited to facilitating the exchange of data by and among the QEs
7. Operating the SDI, including but not limited to (A) collecting, aggregating, and performing quality assurance on data contributed to, or held, or maintained in, or transmitted through the SDI; (B) conducting inquiries and performing discovery with respect to Core SDI Data to assess the scope of Core SDI Data and/or whether it is feasible to fulfill a potential data use request; and (C) analyzing Core SDI Data to assess the feasibility of developing new State-Funded Participant Services or other types of services to be provided through the SHIN-NY; and
8. Purposes permitted by the SHIN-NY Privacy and Security SOP (including but not limited



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to the following: organ procurement organization access, disclosures to payer organizations for quality measures, disclosures to death investigators, research) where data is supplied to or accessed by QEs or NYeC from the PDR for disclosure to SHIN-NY participants.

Other permitted purposes may be added to or removed from this list pursuant to the Statewide Collaboration Process.

Statewide Common Participation Agreement (SCPA) means “...a common agreement, developed using a statewide collaboration process, consistent with any minimum standards set forth in the SHIN-NY policy guidance and approved by the New York State Department of Health, that is used statewide by each qualified entity or by SHIN-NY participants, allowing them to connect to the SHIN-NY statewide data infrastructure either directly or through a contractor, and pursuant to which SHIN-NY participants agree to participate in the SHIN-NY and adhere to SHIN-NY policy guidance, including but not limited to causing patient data to be contributed to the statewide data infrastructure and authorizing the use of patient data for statewide reporting and analytics for public health activities and Medicaid purposes, consistent with applicable law.”⁵

Statewide Data Infrastructure (SDI) means “...the information technology infrastructure provided by the New York State Department of Health, either directly or through contract, to support the aggregation of data provided by qualified entities and SHIN-NY participants, statewide reporting and analytics for public health activities and Medicaid purposes, consistent with applicable law.”⁶ The SDI includes centralized SHIN-NY systems operated or directed by NYeC which serve to aggregate, store, and distribute or otherwise grant access to authorized users of SHIN-NY data.

Statewide Data Use Committee (SDUC) is defined as a committee of the Statewide Collaboration Process designated by the Department with responsibility for the development and amendment of SHIN-NY SOPs (or sections of SOPs) concerning disclosures and uses of data contained in the SDI. The SDUC is additionally responsible for adjudication of SHIN-NY Data Use Requests in accordance with this SOP, except for Narrow Data Use Requests and Urgent Public Health Surveillance Requests, which are reviewed and approved solely by NYeC in accordance with the SOP criteria.

Summary Decision Memo is defined as a memo provided by NYeC to the SDUC and made public as set forth herein, which memo sets forth an analysis of whether a Data Use Request is for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY

⁵ 10 N.Y.C.R.R. § 300.1(m).

⁶ 10 N.Y.C.R.R. § 300.1(m).



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Regulations) or, if applicable, a Narrow Data Use Request or a Data Use Request for Urgent Public Health Surveillance. All Summary Decision Memos shall be in accordance with the form, if any, and otherwise satisfy any requirements established by the SDUC from time to time. All Summary Decision Memos shall be produced in a standard format similar to the form included as Attachment B to this SOP.

Treatment has the meaning set forth in the SHIN-NY Privacy and Security SOPs. As of the date hereof, Treatment is defined as the provision, coordination, or management of health care and related services among health care providers or by a single health care provider and may include providers sharing information with a third party. Consultation between health care providers regarding a patient and the referral of a patient from one health care provider to another also are included within the definition of Treatment.

Treatment Purposes are those related to Treatment as permitted under the SCPA and applicable SHIN-NY SOPs.

Urgent Public Health Surveillance is defined as a public health authority's surveillance of a communicable disease that the Department has determined represents a significant risk to public health. For instance, a declared public health emergency may trigger Urgent Public Health Surveillance but is not required. It is also possible that Urgent Public Health Surveillance may be required to determine whether a public health emergency should or should not be declared. The SDUC may establish additional criteria for determining Urgent Public Health Surveillance.

Description of Standard Operating Procedures

Standard Review Process

Except with respect to Narrow Data Use Requests (as defined above) or Data Use Requests for Urgent Public Health Surveillance (as defined above), which shall be reviewed as set forth below, all Data Use Requests shall be reviewed in accordance with the following procedure:

1. An Authorized Requester submits to NYeC a Data Use Request that meets the requirements described in the definition of "Data Use Request".
2. NYeC will evaluate the following:
 - a. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is for a Public Health Permitted Purpose or a Medicaid Permitted Purpose; and
 - b. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations).



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- c. In connection with NYeC's review, NYeC will make any initial clarifications with the requester.
3. NYeC shall use commercially reasonable efforts to complete its review of the Data Use Request as soon as reasonably practicable, but in any event shall endeavor to complete its review within ten (10) business days after receipt by NYeC of the Data Use Request.
4. If the Data Use Request is determined by NYeC to be other than for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and/or other than in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations), NYeC shall provide notice of denial of the Data Use Request to the requester (including reasons for the denial) and shall so inform the SDUC.
5. If the Data Use Request is recommended by NYeC as for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations), NYeC shall document such recommendation in a draft Summary Decision Memo, shall refer the Data Use Request to the SDUC, and shall so inform the requester.
6. Upon referral to the SDUC by NYeC, the SDUC shall review the Data Use Request and the draft Summary Decision Memo, conduct any additional due diligence the SDUC deems necessary and appropriate (including without limitation discussions with the requester), before finalizing its decision. The SDUC must formally approve or deny the Data Use Request through the Summary Decision Memo before the Data Use Request can proceed. This signoff on the Summary Decision Memo represents the SDUC's official decision.
7. The SDUC shall use commercially reasonable efforts to approve or deny the Data Use Request as soon as reasonably practicable, but in any event shall endeavor to approve or deny the Data Use Request within fifteen (15) business days after receipt by the SDUC of the Data Use Request and draft Summary Decision Memo. The vote of the SDUC will be conducted in accordance with the SDUC Charter.
8. As soon as reasonably practicable, but in any event within three (3) business days after the SDUC's decision, NYeC shall finalize the Summary Decision Memo and provide notice of the SDUC's decision to the requester.
9. NYeC shall be responsible for making the final Summary Decision Memo publicly available online at www.nyehealth.org. NYeC shall endeavor to make such Summary Decision Memo publicly available concurrently with the provision of notice of the SDUC's decision to the requester, but in any event as soon as practicable after such notice is given.

[Expedited Review Process: Narrow Data Use Requests](#)

All Narrow Data Use Requests (as defined above) shall be reviewed in accordance with the following procedure:

1. An Authorized Requester submits to NYeC a Data Use Request that meets the requirements described in the definition of “Data Use Request” and that indicates that the Data Use Request is a Narrow Data Use Request.
2. NYeC will evaluate the following:
 - a. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is for a Public Health Permitted Purpose or a Medicaid Permitted Purpose;
 - b. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations). NYeC will make any initial clarifications with the requester; and
 - c. Whether the Data Use Request is a Narrow Data Use Request.
 - d. In connection with NYeC’s review, NYeC will make any initial clarifications with the requester.
3. NYeC shall use commercially reasonable efforts to make a determination regarding the Data Use Request as soon as reasonably practicable, but in any event shall endeavor to make a determination within five (5) business days after receipt by NYeC of the Data Use Request.
4. If the Data Use Request is determined by NYeC to be other than a Narrow Data Use Request, the Data Use Request will be reviewed in accordance with the Standard Review Process described above, commencing with step 2.
5. If the Data Use Request is determined by NYeC to be a Narrow Data Use Request, but other than for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and/or other than in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations), NYeC shall provide notice of denial of the Data Use Request to the requester (including reasons for the denial) and shall so notify the SDUC.
6. If the Data Use Request is determined by NYeC to be a Narrow Data Use Request and for a Public Health Permitted Purpose or a Medicaid Permitted Purpose and otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations), the Data Use Request shall be deemed approved and NYeC shall document the determination in a Summary Decision Memo. The SDUC does not conduct a formal review and does not approve or deny Narrow Data Use Requests. NYeC shall share the Summary Decision Memo with the SDUC for awareness and provide notice of approval of the Data Use Request to the requester.



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7. NYeC shall be responsible for making the final Summary Decision Memo publicly available online at www.nyehealth.org. NYeC shall endeavor to make such Summary Decision Memo publicly available concurrently with the provision of notice of the SDUC's decision to the requester, but in any event as soon as practicable after such notice is given.

Expedited Review Process: Urgent Public Health Surveillance

All Data Use Requests related to Urgent Public Health Surveillance (*e.g.*, a request for identifiable data on all Emergency Department encounters beginning 6/1/24 with symptoms consistent with H5N1) shall be reviewed in accordance with the following procedure:

1. An Authorized Requester submits to NYeC a Data Use Request that meets the requirements described in the definition of "Data Use Request" and that indicates that the Data Use Request is related to Urgent Public Health Surveillance.
2. NYeC will evaluate the following:
 - a. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is for a Public Health Permitted Purpose;
 - b. Whether the use, disclosure and/or re-disclosure as described in the Data Use Request is otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations); and whether the Data Use Request is related to Urgent Public Health Surveillance.
 - c. In connection with NYeC's review, NYeC will make any initial clarifications with the requester.
3. NYeC shall use commercially reasonable efforts to make a determination regarding the Data Use Request as soon as reasonably practicable, but in any event shall endeavor to make a determination within three (3) business days after receipt by NYeC of the Data Use Request.
4. If the Data Use Request is determined by NYeC to be other than related to Urgent Public Health Surveillance, the Data Use Request will be reviewed in accordance with the Standard Review Process described above, commencing with step 2.
5. If the Data Use Request is determined by NYeC to be related to Urgent Public Health Surveillance and for a Public Health Permitted Purpose and otherwise in compliance with the SCPA, the SHIN-NY SOPs and applicable law (including the SHIN-NY Regulations), the Data Use Request shall be deemed approved and NYeC shall document the determination in a Summary Decision Memo. The SDUC does not conduct a formal review and does not approve or deny Urgent Public Health Surveillance Requests. NYeC shall share the Summary Decision Memo with the SDUC for awareness and provide notice of approval of the Data Use Request to the requester.



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6. NYeC shall be responsible for making the final Summary Decision Memo publicly available online at www.nyehealth.org. NYeC shall endeavor to make such Summary Decision Memo publicly available concurrently with the provision of notice of the SDUC's decision to the requester, but in any event as soon as practicable after such notice is given.

Approved Data Use Requests

Approved Data Use Requests will be operationalized by NYeC, with the SDUC and the SHIN-NY Policy and Technical Advisory Committees providing advice upon request. All Summary Decision Memos will be posted publicly on the NYeC website.

NYeC may implement Modifications of Approved Data Use Requests under the circumstances described in this SOP. If a proposed modification represents a Material Change to an Approved Data Use Request, the requester must submit a new Data Use Request for review and approval in accordance with this SOP.

Oversight and Appeals

Oversight and appeals of SDUC decisions will be conducted pursuant to the SDUC Charter. From and after receipt by NYeC of any successful appeal of previously approved Data Use Request (i.e., a previously approved Data Use Request is deemed to be denied), (a) NYeC and QEs shall not access, use or disclose SDI Data for the purposes described in the applicable Data Use Request; and (b) NYeC shall provide notice to the applicable requester of the successful appeal and shall request that the requester cease access, use or disclosure of SDI Data for the purposes described in the applicable Data Use Request; provided, however, that except as set forth herein, NYeC and QEs shall have no responsibility for any access, use or disclosure of SDI Data by the applicable requester from and after any successful appeal of any previously approved Data Use Request.

Additional SDI Permitted Purposes

In the event that additions are made to the list of the SDI Permitted Purposes, the SDUC shall establish a process, if any, for addressing data use requests related to such additional purpose(s) and amend this SOP accordingly. For the avoidance of doubt, no additional approval process shall be required for use, disclosure or re-disclosure of SDI Data for Treatment and Care Management Purposes and any SDI Permitted Purposes which are required to meet the maintenance and operational needs of the SHIN-NY, as further described under "Limitations" above.

Records

NYeC shall maintain a record of all written documentation related to all Data Use Requests



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(including, but not limited to, all Data Use Requests, all notices to requesters in connection with Data Use Requests, all Summary Decision Memos, and all documentation in connection with the oversight and appeals process) in accordance with NYeC's data retention policies in effect from time to time, or such other policies as may be adopted by the SDUC in accordance with the Statewide Collaboration Process and the SDUC Charter.

Amendment Procedures

Proposals to amend this SOP, including without limitation to reflect amendments or modifications to the definition of SDI Permitted Purposes approved pursuant to the Statewide Collaboration Process, shall be considered, approved and implemented by the SDUC in accordance with the Statewide Collaboration Process and the SDUC Charter. SHIN-NY stakeholders may submit proposals to amend this SOP to the SDUC (or to NYeC staff to provide to the SDUC) for the SDUC's consideration. All amendments to this SOP shall be documented in the Version History section and published in accordance with the Statewide Collaboration Process.

Attachments

- Form of Data Use Approval Request
- Form of Summary Decision Memo

Version History

Version Number	Date Adopted	Summary of Action/Changes
1.0	3/17/25	Approved by Statewide Data Use Committee
	4/01/25	Approved by NYeC Board
	4/02/25	Approved by NYS Department of Health
2.0	12/1/25	Added clarification around the SDI Data Use Approval Process scope, specifically that treatment and care management purposes are allowed and not subject to this process.
	12/4/25	Approved by Statewide Data Use Committee
	2/10/26	Approved by NYeC Board
2.1	3/20/26	Clarified that NYeC can modify the Data Use Request Form as needed for the effective operation of the SDI Data Use Approval Process and that NYeC can modify an Approved Data Use Request to the extent such modifications are not Material.
	3/25/26	Approved by Statewide Data Use Committee
	3/31/26	Approved by NYeC Board
	4/8/26	Approved by NYS Department of Health
2.2	5/7/26	Added as SDI Permitted Purposes those uses permitted by the SHIN-NY Privacy and Security SOP; specified that such uses involving disclosures to state or federal government entities are governed by the SDI Data Use Approval SOP, while such uses involving



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Statewide Health Information Network for New York (SHIN-NY)
Standard Operating Procedure (SOP)

Statewide Data Infrastructure (SDI) Data Use Approval

		disclosures to other SHIN-NY participants are subject to the SHIN-NY Privacy and Security SOP and the SHIN-NY PDR Access SOP
	6/11/26	Approved by Statewide Data Use Committee
	6/25/2026	Approved by NYeC Board
	7/6/2026	Approved by NYS Department of Health