Docusign Envelope ID: 15140CFD-9884-84F1-8027-FA2195162BE1

NEW YORK eHEALTH COLLABORATIVE

SDI Data Use Request: Summary Decision Memo

Administrative Data:

Title: **Identifying Pregnant People Living with HIV for Linkage to Care and Perinatal HIV Transmission Prevention**

Tracking Number: DG-61

Date of Data Use Request Receipt: July 13, 2026

Date NYeC Evaluation Completed: July 20, 2026

Date of NYeC Determination (if applicable): N/A

Date of NYeC Recommendation (if applicable): July 20, 2026

Date of SDUC Decision (if applicable): August 13, 2026

Note: Attached to this Summary Decision Memo is the Data Use Request (and any supporting documentation) provided to NYeC by the NYS Department of Health Authorized Requester

Overview and Description of Request:

The New York State Department of Health, AIDS Institute, Division of Epidemiology, Evaluation, and Partner Services, Bureau of HIV/AIDS Epidemiology submitted this Data Use Request (DG-61) in its capacity as a public health authority conducting HIV/AIDS surveillance and perinatal HIV transmission prevention. The request seeks individually identifiable health data from the Statewide Data Infrastructure (SDI) for the limited purpose of identifying pregnant people living with HIV in New York State to support linkage to clinical care, adherence to antiretroviral therapy, and access to supportive services necessary to prevent perinatal HIV transmission.

For over a decade, perinatal HIV transmission has been maintained at less than 1% among infants born to people living with HIV in New York State. This public health achievement depends on the timely identification of pregnant people living with HIV and rapid connection to care that supports viral suppression. The purpose of this request is to sustain and further reduce that transmission rate by identifying the intersection of pregnancy and HIV positivity across data sources that currently require manual and inefficient review through the SHIN-NY Clinical Viewer.

The requested SDI data will be used to match records for pregnancy status and HIV positivity within a defined temporal window, and to support linkage to care and follow-up activities delivered through the AIDS Institute's existing partner services and case management infrastructure. Information confirmed from SDI data that meets the criteria for incorporation into the State HIV Surveillance Registry will be incorporated into that registry and managed under the applicable PHL Article 27-F and 10 NYCRR Part 63 confidentiality frameworks.

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NYeC Review

Based on NYeC's review, the Data Use Request is found to be:

I. Procedure

☒ Made by an Authorized Requester

Authorized Requester Name: Deirdre Depew

Authorized Requester Title: Director, Bureau of Data Programs and Policy

Authorized Requester's Organization/Entity Name: New York State Department of Health, Office of Health Services Quality and Analytics

☐ Not made by an Authorized Requester

Requester Name: _____

Requester Title: _____

Requester's Organization/Entity Name: _____

II. Purpose

☒ Public Health Permitted Purpose

☒ Data Use Request

☐ Narrow Data Use Request

☐ Data Use Request for Urgent Public Health Surveillance

☐ Medicaid Permitted Purpose

☐ Data Use Request

☐ Narrow Data Use Request

☐ Other (brief description: _____)

III. Compliance

	Compliant	Not Compliant	Not Applicable
Statewide Common Participation Agreement (SCPA)	☒	☐	☒

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Data Use and Contribution Agreement (DUCA) *	☒	☐	☐
SHIN-NY Regulations & Applicable SHIN-NY SOPs	☒	☐	☐
Applicable Law	☒	☐	☐

Justification for Compliance Findings:

The Department's authority to access the requested SDI information for this use case is established under its role as a Public Health Authority (45 C.F.R. §§ 164.501 and 164.512(b)). The Department is the State agency responsible for HIV/AIDS surveillance, perinatal HIV transmission prevention, and HIV related public health follow up in the State, pursuant to its general public health authority (NYS Public Health Law (PHL) § 201), PHL Article 21 (Control of Acute Communicable Diseases), PHL 2(1)(n), 10 NYCRR Part 63 (HIV Reporting and Partner Notification), and 10 NYCRR Part 23 (Sexually Transmissible Disease Control). Confidentiality of HIV related information is governed by PHL Article 27-F, which strictly limits disclosure of HIV related information but expressly permits disclosure to the Department for authorized public health activities including surveillance case investigation, epidemiological monitoring, and care improvement activities with regard to people living with HIV/AIDS. SHIN-NY Privacy Policy Sections 1.2.2(b)(vi) and (vi) permit disclosure of such records without affirmative consent for purposes allowed by 10 NYCRR Parts 63 and 23, respectively. The AIDS Institute is the operational home for HIV/AIDS surveillance and perinatal transmission prevention within the Department and conducts these activities as a core statutory public health function.

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The Department's request for identified SHIN-NY data will be used by the AIDS Institute without affirmative consent, for public health surveillance and related public health follow up activities, specifically to identify individuals who are both pregnant and living with HIV within the defined temporal window and to support linkage to care and perinatal HIV transmission prevention through the AIDS Institute's existing partner services and case management infrastructure operating under 10 NYCRR Parts 23 and 63. Information received under this request will be handled in accordance with the ongoing confidentiality requirements of PHL Article 27-F. The disclosure of identifiable SHIN-NY data for the case identification, linkage to care, and perinatal transmission prevention purposes described herein is consistent with the SHIN-NY Regulations and SHIN-NY SOPs governing disclosures for Public Health Permitted Purposes, and falls within the surveillance and follow-up activities authorized by PHL Articles 21 and 27-F, 10 NYCRR Parts 23 and 63, and SHIN-NY P&Ps § 1.2.2(b)(v) and (vi).

Consistent with this Data Use Request, identified data obtained through this approval will be accessed only by authorized AIDS Institute personnel within the Bureau of HIV/AIDS Epidemiology and the Division of Epidemiology, Evaluation, and Partner Services who are engaged in HIV surveillance, partner services, and perinatal transmission prevention activities. No external parties will have access to identifiable data. Information confirmed from SDI Data that meets the criteria for incorporation into the State HIV Surveillance Registry will be incorporated and managed under the registry's existing PHL Article 27-F and 10 NYCRR Part 63 confidentiality framework. Raw SHIN-NY data files will be destroyed after casework is complete, in accordance with Department confidentiality policies, including APPM DLA–022.

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For clarity, this Summary Decision Memo addresses only the Department's request for identified SHIN-NY data for the public health surveillance, linkage to care, and perinatal HIV transmission prevention purposes described in the approved Data Use Request. Information incorporated into the State HIV Surveillance Registry through this approval becomes part of the registry's protected dataset and is governed by the confidentiality provisions of PHL Article 27-F and 10 NYCRR Part 63, as well as the ongoing obligations of the SCPA, DUCA, SHIN-NY Regulations, and SHIN-NY SOPs to the extent such obligations apply. Use of registry data for surveillance, investigation, care coordination, and required public health reporting is authorized within the statutory framework governing the registry. Any aggregate or deidentified outputs derived from data received under this request will be limited to internal Department program monitoring and required public health reporting, produced in aggregate form sufficient to prevent re-identification, and will not be used for public-facing products. Any other proposed use, redisclosure, sharing, onward provision of data received under this request, including any research use, or expansion of scope beyond the purposes set forth here would require separate authorization.

The request is reasonably related to the stated public health objective and is consistent with HIPAA's minimum necessary standard under 45 C.F.R. § 164.514(d), as well as the limitations and conditions contemplated by the SCPA, DUCA, SHIN-NY Regulations, and SHIN-NY SOPs.

NYeC Determination: Narrow Data Use Request

☐ Approved

☐ Denied (description of reason[s]):

_____

_____

NYeC Determination: Urgent Public Health Surveillance Data Use Request

☐ Approved

☐ Denied (description of reason[s]):

_____

_____

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NYeC Recommendation to SDUC: Data Use Request

☒ Approval

☐ Denial (description of reasons[s]):

_____

_____

NYeC Head of Enterprise Initiatives and Partnerships

Signed by: CB567B7186BD443...

Date: 7/20/2026

NYeC Privacy & Compliance Officer

Signed by: 0CADF6960C7C420...

Date: 7/20/2026

SDUC Determination

☒ Approved

☐ Denied (description of reason[s]):

_____

_____

Signed by: 0CB111D9525B412...

SDUC Chair

Date: 8/25/2026

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Project Name: Identifying Pregnant People Living with HIV for Linkage to Care and Perinatal HIV Transmission Prevention **Tracking ID:** DG-61	
A. Request Overview	
Item	***Response***
1) **Authorized Requester Information Description** Identification of the Requester's Organization and a brief description of the requester type (e.g., public health authority (PHA); PHA contractor; government agency (specify) etc.)	New York State Department of Health (NYSDOH), AIDS Institute, Division of Epidemiology, Evaluation, and Partner Services, Bureau of HIV/AIDS Epidemiology. This request is submitted by a public health authority engaged in legally authorized public health surveillance, investigation, and programmatic follow-up activities.
2) **Project Description** Summary of the project including how this data will be used.	For over the past decade, perinatal transmission of HIV has been less than one percent among infants born to people living with HIV in New York State. Viral suppression among birthing parents is key in preventing perinatal HIV transmission. To sustain and further reduce transmission, this project seeks to identify when people living with HIV are pregnant to facilitate clinical care, adherence to antiretroviral therapy, and supportive services to achieve and maintain viral suppression.
3) **Permitted Purpose Description**	☑ Public Health Activity Permitted Purpose ☑ Data Use Request with Individually Identifiable Health Info (e.g., PHI) ☐ Narrow Data Use Request ☐ Data Use Request for Urgent Public Health Surveillance ☐ Medicaid Permitted Purpose ☐ Other

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4) **Description of Intended Use** Describe the intended use of data, including any intended disclosure or re-disclosure, and the basis on which the intended use, disclosure or re-disclosure is for a Public Health Activity Permitted Purpose or a Medicaid Permitted Purpose and otherwise in compliance with the Statewide Common Participating Agreement (SCPA), the Data Use and Contribution Agreement (DUCA), the SHIN-NY Regulations and SHIN-NY Standard Operating Procedures (SOPs) and applicable law.	The data will be used to identify pregnant people living with HIV for linkage to care and perinatal HIV transmission prevention. This supports ongoing surveillance and follow-up to assist individuals with clinical care, adherence to antiretroviral therapy, and supportive services. Linkage to care and follow up activities are conducted through the AIDS Institute's existing partner services and case-management infrastructure, consistent with 10 NYCRR Part 63 and Part 23 protocols. The information will not be used for public-facing products. No re-disclosure of the data will occur.
5) **Target Population Inclusion** Specify the criteria used for the dataset. Typical inclusion criteria are: demographic, clinical, and geographic characteristics.	All of New York State; individuals who are both pregnant and living with HIV. Individuals are included when the pregnancy encounter occurs within 40 weeks before or after a positive HIV test, or when the positive HIV test occurs within 40 weeks before or after a pregnancy encounter.
6) **Target Population Exclusion** Specify the criteria that would exclude the case/data from being included in the dataset. (For example, if you are looking at residents of certain counties or only looking for persons over the age of 65.)	Duplicate records are excluded. Patients may be re-included if they meet criteria again after 20 weeks from initial inclusion.
7) **What law, regulation, rule or agreement grants the authority to obtain this information?** Identify, in detail, the laws, regulations, contracts, SHIN-NY SOPs and other governing documents that allow and authorize access to the data requested.	Public Health Law Articles 21 and 27-F; 10 NYCRR Part 63; 10 NYCRR Part 23; PHL § 2(1)(n). These authorities provide the regulatory scheme that permits disclosure of protected health information to public health authorities without affirmative consent for authorized public health activities including surveillance, case investigation, epidemiological monitoring, and care

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	improvement with regard to people with HIV/AIDS. SHIN-NY P&P Section 1.2.2(b)(v) permit disclosure of such records without Affirmative Consent for purposes allowed by 10 NYCRR Part 23.
8) **Is this data currently being supplied to Requester from another source? *** (yes/no)	No. Similar information may be accessible through the QE Clinical Viewers, but it is a manual and inefficient manner to obtain the records.
9) *If Yes, explain where data is being supplied from and why Statewide Data Infrastructure (SDI) Data is being requested. (SDI data is data held in the "statewide repository" referred to in 10 NYCRR §300.2(f)(5))	Not applicable
10) **What is the expected start date of this project?** The date when the project work is expected to begin (Mo/Day/Yr.).	09/01/2026
11) **Is this request time-sensitive and/or critical? *** (yes/no)	No
12) *If time-sensitive or critical, explain	Not applicable
13) **When is this information needed?** The date by which Requestor would need the report/data (Mo/Day/Yr.).	09/01/2026
14) **What is the expected end date of this project?** The date when the project is expected to end (Mo/Day/Yr.).	N/A — This is an ongoing surveillance and follow-up effort with no predefined end date.
(B) Technical Specifications Data Use Request	
1) **What data elements are needed?** Describe all the data fields required for your project (example: Date of birth, diagnosis codes, etc.)	See Appendix A. Requested elements include first name, last name, date of birth, street address, ZIP code, medical record number; pregnancy-related encounter data, including facility, dates, ICD-10/SNOMED indicators, and test results; and HIV test

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	data, including facility, dates, LOINC, descriptions, and positive result values. Pregnancy indicators must confirm pregnancy, not suspected pregnancy. HIV results must indicate positive values.
2) **Is the data being requested 1) individually identifiable health data, 2) limited data set (LDS)* or 3) de-identified*? (select from drop down).** *If the data requested is a Limited Data Set (LDS) or de-identified data, Requester must complete attestation below in Section D(3)(c).	Individually identifiable health data
3) **Proposed delivery method*** (select from drop-down)	NYeC Secure File Transfer
4) *If selected "other" above for delivery method, please explain the proposed delivery method. Only methods with secure encryption mechanisms will be accepted.	Not applicable
5) **What is the requested format for the data?** (examples include XLS, txt, CSV)	CSV (.CSV)
6) **What safeguards will you put in place to protect the data?**	Data will be protected in accordance with HIPAA, NYS Personal Privacy Protection Law, SHIN-NY privacy and security policies, DOH APPM policies, DEEP confidentiality protocols, AIDS Institute confidentiality protocols, and CDC data security guidelines. Access to identifiable data received under this request will be limited to authorized AIDS Institute personnel engaged in HIV surveillance, partner services, and perinatal transmission prevention activities. No external parties will have access to identifiable data..
7) **How will files be handled/stored/deleted at the end of the project?**	Documents containing protected health information will be disposed of in accordance with DOH confidentiality policies, including APPM DLA-022, to ensure protection of confidentiality.

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	Information confirmed from SHIN-NY data that meets the criteria for incorporation into the State HIV surveillance registry will be incorporated and managed under the surveillance registry's existing PHL Article 27-F and 10 NYCRR Part 63 confidentiality framework. Raw SHIN-NY transmittal files will be destroyed after case work is complete.
8) **Select "Yes" to indicate adherence to the standard of minimum necessary data requests. (This field cannot be blank.)**	Yes
(C) Program/Project Contact Information	
1.Program Lead Contact Information	
Name (First, Last):	[redacted]
Bureau/Unit:	AIDS Institute, Division of Epidemiology, Evaluation, and Partner Services (DEEP), Bureau of HIV/AIDS Epidemiology
Email:	[redacted]@health.ny.gov
Phone Number:	[redacted]
2. Other Project Team Members	
a) Team Member 1 (Name, Employer, Contact Info)	[redacted] — Research Scientist IV, Surveillance Coordinator, AIDS Institute, DEEP, Bureau of HIV/AIDS Epidemiology; [redacted]@health.ny.gov
b) Team Member 2 (Name, Employer, Contact Info)	[redacted] — Director, AIDS Institute, DEEP, Bureau of HIV/AIDS Epidemiology; [redacted]@health.ny.gov
c) Team Member 3 (Name, Employer, Contact Info)	[redacted] — Research Specialist III, AIDS Institute, DEEP, Bureau of HIV/AIDS Epidemiology; [redacted]@health.ny.gov

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d) Team Member 4 (Name, Employer, Contact Info)	[redacted] — Senior Database Engineer, AIDS Institute, DEEP, Bureau of HIV/AIDS Epidemiology; [redacted]@health.ny.gov
e) Team Member 5 (Name, Employer, Contact Info)	[redacted] — Evaluation Specialist III, AIDS Institute, DEEP, Bureau of HIV/AIDS Epidemiology; [redacted]@health.ny.gov

(D) Data Use Request Authorized Requester Attestation & Agreement Form	
Name of Requester's Organization: New York State Department of Health, AIDS Institute, Division of Epidemiology, Evaluation, and Partner Services	
1) Authorized Requester Information	
Name: [redacted]	
Title: Research Scientist IV, Surveillance Coordinator	
Email: [redacted]@health.ny.gov	
Phone Number:	
2) Attestations: Authorized Requester attests to the following:	
a) This Data Use Request meets the following criteria:	
i. Request is for a **Public Health Activities** by Public Health Authority. **OR** Request is for a **Medicaid Permitted Purpose**	☑ ☐
ii. Request is in compliance with the SCPA, DUCA, SHIN-NY Regulations and SHIN-NY SOPs.	☑
iii. Request is in compliance with applicable law.	☑
iv. Data elements requested meet the standard of minimum necessary.	☑
b) Safeguards and Protections Attestation:	
Appropriate safeguards and internal controls will be used for data access and use, security and privacy.	☑
c) Data Classification and Use Attestation (for Narrow Data Requests)	
(select one or both, or neither) **HIPAA Limited Data Set 45 C.F.R. 164.514(e)** **De-Identified Data (45 C.F.R. 164.514(b)(2))**	☐ ☐

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Based on the Data Classification(s) identified above, the Authorized Requester attests and agrees to the following:

- The data will be used solely for the **permitted purpose(s)** described in this approved SDI Data Use Request and as authorized under the SCPA, DUCA, SHIN-NY Regulations, and SHIN-NY SOPs and applicable law.
- Requester may use and disclose a Limited Data Set solely for the purpose(s) expressly described in, and approved through this SDI Data Use Request, and only to the extent such use or disclosure is permitted under applicable law and consistent with 45 C.F.R. § 164.514(e). Requester shall not use or further disclose the Limited Data Set in any manner that would violate the HIPAA Privacy Rule if done by a covered entity.
- Access to and receipt of a Limited Data Set shall be **limited to those workforce members, agents, contractors, and other specifically authorized persons** identified by Requester as having a need to know the information for the approved purpose(s), and no other person or entity may use or receive the Limited Data Set except as expressly permitted by this SDI Data Use Request and applicable law.
- The data will **not be re-identified**, and no third party will be permitted to re-identify or attempt to re identify individuals whose information is included in the data. If the Requester becomes aware of any actual or attempted re-identification of individuals or data, Requester will notify NYeC immediately.
- No individual whose information is included in the data may be contacted in association with the use case described and approved in this SDI Data Use Request., nor will any third party be permitted to contact or attempt to contact such individuals based solely on SDI Data.
- Any **agents, contractors, or downstream recipients** with access to the data will agree and be subject to use, disclosure, and safeguard obligations no less protective than those set forth in this Data Use Request, the Statewide Common Participation Agreement, and applicable law.
- Appropriate **administrative, technical, and physical safeguards** will be used to prevent any use or disclosure of the data not permitted by this Data Use Request or applicable law, and any un authorized use or disclosure of which Requester becomes aware will be reported to NYeC in accordance with the SCPA, and SHIN-NY SOPs.
- The data will not be used for marketing purposes or sold, licensed, or otherwise disclosed in exchange for remuneration, except as permitted by HIPAA and applicable law, and only with prior written consent of NYeC.
- The Requester will not, and will not permit any third parties to use de-identified data for any purpose other than those permitted in this Data Use Request or otherwise as permitted by law.
- Requester shall otherwise comply in full with 45 C.F.R. § 164.514(e)(4)(ii).
- Upon expiration, suspension or termination of this Data Use Request, Requester shall immediately cease all use and disclosure of all SDI Data and comply with any instructions from NYeC regarding continued retention, return, destruction, or other handling of the data, in accordance with this Data Use Request, the SCPA, DUCA, SHIN NY Regulations, SHIN NY SOPs, and applicable law.

d) Attestations Regarding Potential Violation of this Data Use Request

i. The New York State Department of Health in coordination with NYeC, reserves the right to investigate any actual or suspected breach, or improper access, use, or disclosure of data by Requester or any person acting on Requester's behalf stemming from this Data Use Request.	☐

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ii. Requester acknowledges and agrees that NYeC may, following notice to and consultation with the Department, suspend, terminate, or revoke Requester's access to SDI Data immediately upon notice, or immediately without prior notice where NYeC determines prompt action is necessary, if NYeC determines in its reasonable discretion that Requester has violated this Data Use Request, the SCPA, DUCA, SHIN-NY Regulations, SHIN-NY SOPs, or applicable law. Requester shall cooperate with the Department and NYeC in investigating and mitigating any such violation.	☐
4. Authorized Requester Signature: Deirdre Depew	
Click or tap here to enter text. [redacted] Depew Digitally signed by [redacted] Date: 2026.07.13 13:03:42 -04'00'	**Date of Signature:** Click or tap to enter a date.

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Appendix A - Data Elements

This appendix is intended to capture the individual data elements necessary to fulfill your use case. For additional information on data standards, please refer to this SHIN-NY Public Health Access: Data Lake Data Standards page.

Requested Data Elements

Please download this Excel Workbook and list each of the data elements required to fulfill your use case in the Appendix A - Data Elements tab. Please review the example and add additional rows to the table as necessary to fulfill your use case.

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NEW YORK STATE | Department of Health

Appendix A - Data Elements

Data Element Class	Data Element	Data Element Standard	Data Standard Code Values*
Patient Demographics/Information	First Name	-	-
Patient Demographics/Information	Last Name	-	-
Patient Demographics/Information	Date of Birth		
Patient Demographics/Information	Street Address		
Patient Demographics/Information	ZIP code		
Patient Demographics/Information	medical record number		
Laboratory & Clinical Notes	name of facility of encounter for ICD-10/SNOMED CT indicating pregnancy		
Laboratory & Clinical Notes	date of encounter for ICD-10/SNOMED CT indicating pregnancy		
Laboratory & Clinical Notes	ICD-10/SNOMED CT that indicates pregnancy coming from the laboratory results, clinical notes, or any other section of the electronic medical record that could contain the ICD-10/SNOMED CT	ICD-10/SNOMED CT	Based on equivalent ICD-10 diagnostic codes attached separately, or SNOMED equivalent. These should be indicators someone is pregnant, not just that pregnancy is suspected. If based on pregnancy test, ultrasound, etc. then the result of the test or procedure must indicate pregnant.
Laboratory	if a pregnancy test, the result value	ICD-10/SNOMED CT	Based on equivalent ICD-10 diagnostic codes attached separately, or SNOMED equivalent. These should be indicators someone is pregnant, not just that pregnancy is suspected. If based on pregnancy test, ultrasound, etc. then the result of the test or procedure must indicate pregnant.
Laboratory	name of facility of encounter for positive HIV test		
Laboratory	date of encounter for positive HIV test		
Laboratory	LOINC of positive HIV test	LOINC	See attached list of LOINCs "HIV_LOINC_20260605.xlsx". Where this LOINC is indicated, the result also needs to be positive.
Laboratory	LOINC description	LOINC	Description of the type of HIV test for that LOINC
Laboratory	result value	LOINC	Result value for the LOINC of the HIV test (should only be values that indicate positive).

*Notes: *The 'Data Standard Code Values' column is optional.*