Docusign Envelope ID: B17AA39C-D258-83C5-8268-143585409FEE

NYeC
NEW YORK eHEALTH COLLABORATIVE

SDI Data Use Request: Summary Decision Memo

Administrative Data:

Title: Parkinson's Disease Prevalence in New York State

Tracking Number: DG-55

Date of Data Use Request Receipt: 4/24/2026

Date NYeC Evaluation Completed: 4/24/2026

Date of NYeC Determination: 4/24/2026

Date of NYeC Recommendation (if applicable):

Date of SDUC Decision (if applicable): n/a

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:

This Public Health Data Access Request supports the Department's surveillance of Parkinson's disease pursuant to Article 20-B of the Public Health Law. Among its provisions, Article 20-B requires mandatory reporting of diagnoses by health care providers, establishes a Parkinson's disease registry, allows for data sharing between the Department and local health officers and the federal Centers for Disease Control and Prevention, and directs the Department to publish information on the incidence and prevalence of Parkinson's by county and demographic information.

The New York State Department of Health will monitor and calculate Parkinsonism and Parkinson's Disease prevalence in New York State by utilizing data from a Limited Data Set from the New York State Statewide Health Information Network of New York (SHIN-NY) to support the development of a statewide Parkinson's Disease Prevalence Report by age, sex/gender, condition type, and county.

The project goal is to develop a Parkinson's Disease Prevalence Report that will include prevalence levels across New York State showing charts, graphs, and trends at both the State and subpopulation levels.

For clarity, the instant request does not seek to establish or populate the Parkinson's Disease Registry itself, nor does it request identifiable patient-level data. Rather, the request is limited to the use of SHIN-NY data solely to support the Department's development of a statewide Parkinson's Disease Prevalence Report.

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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: Dierdre Depew

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

Authorized Requester's Organization/Entity Name: Office of Health Services Quality Management, NYS Department of Health

☐ 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

☒ HIPAA Limited Data Set

☐ De-Identified Data

☐ Data Use Request for Urgent Public Health Surveillance

☐ Medicaid Permitted Purpose

☐ Data Use Request

☐ Narrow Data Use Request

☐ HIPAA Limited Data Set

☐ De-Identified Data

☐ Other (brief description: _____)

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III. Compliance

	Compliant	Not Compliant	Not Applicable
Statewide Common Participation Agreement (SCPA)	☒	☐	☐
Data Use and Contribution Agreement (DUCA) *	☒	☐	☐
SHIN-NY Regulations & Applicable SHIN-NY SOPs	☒	☐	☐
Applicable Law	☒	☐	☐

Justification for Compliance Findings:

The instant request should be approved as a Narrow Data Use Request because it seeks a HIPAA compliant Limited Data Set ("LDS") for a defined public health surveillance purpose: supporting the Department's statutory obligation to monitor and report Parkinson's disease incidence and prevalence, and to publish summary reports in which individuals cannot be identified.

Article 20-B of the NYS Public Health Law establishes the State Parkinson's Disease Registry and expressly authorizes the Department's public health surveillance activities related to Parkinson's disease and related conditions called "Parkinsonisms," including the use of data to monitor incidence and prevalence and to publish summary reports in which individuals cannot be identified. (N.Y. Pub. Health L. §§ 2010, 2011, 2012 and 2013).

As a Public Health Authority (45 C.F.R. § 164.501; N.Y.S. Pub. Health L. § 206(1)(d)), the Department's request to use SHIN-NY data to support its Article 20-B obligations is a proper public health purpose for which SHIN-NY data can be used. The Statewide Data Infrastructure (SDI) Data Use Approval Process SOP ("SDI Data Use Approval Process SOP") allows the use of SDI Data for "Public Health Permitted Purposes" which includes disclosures of PHI "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." *See* SDI Data Use Approval Process SOP, pp 5,8 (referencing 10 N.Y.C.R.R. 300.1(o)). While the inclusion of identifiable data in a Parkinsons's Disease Registry to support the full range of uses contemplated by Article 20-B would require affirmative patient consent, the use of the LDS to support incidence and prevalence reporting is expressly contemplated by Article 20-B and permitted without such patient consent.

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Consistent with the SDI Data Use Approval Process SOP, this request is properly classified as a Narrow Data Use Request under a Public Health Permitted Purpose, and the request is structured to meet both SHIN-NY requirements and HIPAA's requirements for the use and disclosure of a LDS. See SDI Data Use Approval Process SOP, p 4. Specifically, a review of the requested data elements for this use case in **DG-55 Appendix A** confirms the requested data elements are limited to those permissible in a LDS and exclude direct identifiers, consistent with 45 C.F.R. § 164.514(e)(2). Also, LDS may be used and disclosed for the stated purpose provided that the required data use agreement ("DUA") is in place. See 45 C.F.R. § 164.514(e). The Requester's attestations in Exhibit A, including restrictions on use and re-disclosure, safeguards, and a prohibition on re-identification or contact, satisfy the DUA requirements for an LDS. See 45 C.F.R. § 164.514(e)(4).

Finally, the request satisfies HIPAA's "minimum necessary" standard because it seeks only the limited demographic and clinical elements required to generate statewide incidence and prevalence estimates and to publish aggregated findings, rather than identifiable patient-level records. See 45 C.F.R. § 164.502(b).

For the foregoing reasons, this request may be approved as a Narrow Data Use Request because it is consistent with applicable law, HIPAA, and the SHIN-NY Regulations and applicable SHIN-NY SOPs.

NYeC notes that this request represents the Department's first request to use the SHIN-NY to assist with its obligations under Article 20-B. At this stage, the specific criteria and logic required to generate the Parkinson's Disease Prevalence Report are anticipated to be developed and refined over time. Any alteration of scope of the SDI Permitted Purpose(s) or the intended uses for which SDI Data was approved to be used, disclosed, or redisclosed, modification that would provide access to additional SDI data elements, or modification that would change the type of data requestsed (i.e., identified, LDS or de-identified) beyond those described in this request would constitute "Material Changes to an Approved Data Use Request" that would require additional review and approval in accordance with the SDI Data Use Approval Process SOP.[1]

[1] Note: In March 2026, NYeC proposed mendments to the SDI Data Use Approval Process SOP that would, among other things, permit NYeC to make "Modficiations of an Approved Data Use Request" without SDUC approval where such modifications are not "Material Changes to an Approved Data Use Request." As of April 3, 2026, those proposed amendments have been approved by the SDUC and the NYeC Board and are pending approval from the Department.

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NYeC
NEW YORK eHEALTH COLLABORATIVE

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]):

_____

_____

NYeC Recommendation to SDUC: Data Use Request

☐ Approval

☐ Denial (description of reasons[s]):

_____

_____

DocuSigned by:
Charlie Feldman
0CADF6960C7C420... — 4/24/2026

NYeC Legal — Date

DocuSigned by:
Alison Bianchi
1C1BB9F6120346A... — 4/24/2026

NYeC Privacy & Compliance Officer — Date

SDUC Determination

☐ Approved N/A

☐ Denied (description of reason[s]):

_____ _____

SDUC Chair — Date

Project Name: Parkinson's Disease Prevalence in New York State **Tracking ID:** DG-55	
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.)	Bureau of Data Programs and Policy, Office of Health Services Quality Management (Public Health authority under HIPAA)
2) **Project Description** Summary of the project including how this data will be used.	Effective as of March 13, 2025, new provisions were added to the Public Health Law (§§2010-2014) with a stated goal of developing a registry of people with Parkinson's to help researchers identify high-risk groups, detect prevalence patterns among the New York population, and uncover disparities in treatment. The New York State Department of Health will monitor and calculate Parkinsonism and Parkinson's Disease prevalence in New York State by utilizing, data from a Limited Data Set from the New York State Statewide Health Information Network for New York (SHIN-NY) to support the development of a statewide Parkinson's Disease Prevalence Report by age, sex/gender, condition type, and county. The project goal is to develop a Parkinson's Disease Prevalence Report that will include prevalence levels across New York State showing charts, graphs, and trends at both the State and subpopulation levels. The subpopulations for review aim to determine trending prevalence based on patient county, region, sex/gender, and by year. It shall be noted that the criteria and logic is not currently fully defined for individuals with Parkinson's Disease and continued efforts are anticipated to refine and modify the details.

3) **Permitted Purpose Description**	☒ Public Health Activity Permitted Purpose ☐ Data Use Request with Individually Identifiable Health Info (e.g. PHI) ☒ Narrow Data Use Request (e.g. de-identified; LDS). If this box is checked, Requester must complete attestation below in Section D(3)(c). ☐ Data Use Request for Urgent Public Health Surveillance ☐ Medicaid Permitted Purpose ☐ Data Use Request ☐ Narrow Data Use Request (e.g., de-identified; LDS) If this box is checked, Requester must complete the attestation below in D(3)(c). ☐ Other: Click or tap here to enter text.
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 Office of Health Services Quality and Analytics will assess prevalence and high-level characteristics of those diagnosed with Parkinson's Disease based on criteria such as county and location, age, race and ethnicity using existing data to reduce burden on providers in accordance with Public Health Law.
5) **Target Population Inclusion** Specify the criteria used for the dataset. Typical inclusion criteria are: demographic, clinical, and geographic characteristics.	• All New York State residents. • Individuals diagnosed with Parkinson's Disease or malignant neurological diagnoses codes. • For all patients with multiple diagnoses for Parkinson's Disease or malignant neurological diagnoses codes, please include only the first diagnosis date. See the supplemental document "DG-55 –Appendix A – Data Elements," attached hereto for further information and details ("Appendix A").
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.)	Individuals under the age of 18.

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.	In December 2024, Governor Hochul signed Senate Bill S4674A into law which requires the State to create a Parkinson's Disease Registry. As a Public Health Authority (45 C.F.R. § 164.501; N.Y.S. Pub. Health L. § 206(1)(d)), the Department's request to use a Limited Data Set from SHIN-NY data to support its Article 20-B obligations is a proper public health use case in the SHIN-NY. The Statewide Data Infrastructure (SDI) Data Use Approval Process SOP ("SDI SOP") allows for the Department to access and use SDI Data for "Public Health Permitted Purposes" which includes disclosures of PHI 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." See SDI SOP, pp 4, 8 (referencing 10 N.Y.C.R.R. 300.1(p)). While the inclusion of identifiable data in a Parkinsons's Disease Registry to support the full range of uses contemplated by Article 20-B would require affirmative patient consent, the use of the Limited Data Set in this narrow use case to support incidence and prevalence reporting is expressly contemplated by Article 20-B and permitted without such patient consent. N.Y. Pub Health L. § 206(1)(j) further confirms the Department's authority to use such data for public health purposes. The Department's access to SHIN-NY data for this request is permitted without patient consent under N.Y. Pub. Health L. § 206(1)(j) and Article 20-B, provided all confidentiality requirements are met and published data cannot reasonably be used to reidentify individuals. Additionally, this request adheres to the HIPAA minimum necessary standard, meaning only the least amount of information required to accomplish the intended public health purpose is accessed and used, thereby further protecting individual privacy.
8) **Is this data currently being supplied to Requester from another source? *** (yes/no)	No
9) *If Yes, explain where data is being supplied from and why Statewide Data Infrastructure (SDI) Data is being requested.	N/A

(SDI data is data held in the "statewide repository" referred to in 10 NYCRR §300.2(f)(5))	
10) **What is the expected start date of this project?** The date when the project work is expected to begin (Mo/Day/Yr.).	**5/1/2026**
11) **Is this request time-sensitive and/or critical? *** (yes/no)	Yes
12) *If time-sensitive or critical, explain	To implement the new provisions in Public Health Law being passed, efforts are needed to assess disease prevalence across the various datasets such as geography and demographics for supporting awareness, research, and evaluation.
13) **When is this information needed?** The date by which Requestor would need the report/data (Mo/Day/Yr.).	**5/1/2026**
14) **What is the expected end date of this project?** The date when the project is expected to end (Mo/Day/Yr.).	**To be determined**
(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**.
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).	**2) Limited Data Set**
3) **Proposed delivery method*** (select from drop-down)	Secure File Transfer 2.0 through the NYS Health Commerce System (HCS)
4) *If selected "other" above for delivery method, please explain the proposed delivery method. Only methods with secure encryption mechanisms will be accepted.	N/A

5) **What is the requested format for the data?** (examples include XLS, txt, CSV)	.CSV or .XLSX
6) **What safeguards will you put in place to protect the data?**	The Limited Data Set is to develop a Parkinson's Disease Prevalence Report that will include prevalence levels across New York State showing charts, graphs, and trends at both the State and subpopulation levels. All confidentiality requirements will be met and the Department will ensure that published data cannot reasonably be used to re-identify individuals.
7) **How will files be handled/stored/deleted at the end of the project?**	Data will be sent via secure file transfer on HCS. Stored on secure sever only accessible by those approved under the team.
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:	Office of Health Services Quality and Analytics
Email:	[redacted]@health.ny.gov
Phone Number:	[redacted]
2. Other Project Team Members	
a) Team Member 1 (Name, Employer, Contact Info)	[redacted] New York State Department of Health [redacted]@health.ny.gov
b) Team Member 2 (Name, Employer, Contact Info)	Click or tap here to enter text.
c) Team Member 3 (Name, Employer, Contact Info)	Click or tap here to enter text.
d) Team Member 4 (Name, Employer, Contact Info)	Click or tap here to enter text.
e) Team Member 5 (Name, Employer, Contact Info)	Click or tap here to enter text.

(D) Data Use Request Authorized Requester Attestation & Agreement Form	
1) Name of Requester's Organization: Office of Health Services Quality and Analytics	
2) Authorized Requester Information	
Name: [redacted]	
Title: Director, Bureau of Data Programs and Policy, Office of Health Services Quality and Analytics	
Email: [redacted]@health.ny.gov	
Phone Number: [redacted]	
3) 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))**	☒ ☐

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 unauthorized 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.	☒
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:

Click or tap here to enter text.	**Date of Signature:** 4/24/2026

Appendix A - Data Elements

This appendix is intended to capture the individual data elements necessary to fulfill your use
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 yo
Please review the example and add additional rows to the table as necessary to fulfill your u

e case. For additional information on data standards,

our use case in the Appendix A - Data Elements tab.
se case.

NEW YORK STATE | Department of Health

Appendix A - Data Elements

Data Element Class	Data Element
Problems	Problems
Encounter Information	Encounter Diagnosis
Encounter Information	Encounter Time
Encounter Information	Encounter Type
Clinical Notes	Discharge Summary Note
Diagnostic Imaging	Diagnostic Imaging Test
Facility Information	Facility Type
Health Status Assessments	Functional Status
Health Status Assessments	Disability Status
Orders	Laboratory Order
Orders	Diagnostic Imaging Order
Orders	Clinical Test Order
Orders	Procedure Order
Patient Demographics/Information	Date of Birth
Patient Demographics/Information	Sex
Patient Demographics/Information	County of Residence

Problems	Date of Diagnosis
Patient Demographics/Information	Race
Patient Demographics/Information	Ethnicity
Laboratory	Tests
Laboratory	Result Status

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

s

Data Element Standard
ICD-10-CM
ICD-10-CM
-
-
LOINC
LOINC
-
LOINC
LOINC
-
-
-
-
-
SNOMED
-

-
CDC Race and Ethnicity Code Set Version 1.2
CDC Race and Ethnicity Code Set Version 1.2
LOINC
-

Data Standard Code Values*
G20.0 G20.A1 G20.A2 G20.B1 G20.B2 G20.C G13.8 G23.2 G23.3 G90.3 G23.1 G31.85 G31.83 G21.0 G21.11 G21.19 G21.2 G21.3 G21.4 G21.8 G21.9
-
-
** The team is unsure how imaging data and results are stored for use*
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dd/mm/yyyy
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dd/mm/yyyy
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