Neurodegenerative Disease Guide to Reporting

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Please contact us at CDSRBHelp@cdph.ca.gov
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1. Introduction

In 2018 and 2021, California established Health and Safety Code (HSCs) section 103870 Chapter 1.6 and section 103871 Chapter 1.7, respectively. The HSCs mandate collection and reporting of Parkinson's Disease and other neurodegenerative diseases such as Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Alzheimer's disease, and Huntington's disease. They also require the California Department of Public Health (CDPH) to specify which neurodegenerative diseases will be collected, to establish a system to collect neurodegenerative disease information to determine its' incidence and prevalence in California, and to share information about reporting neurodegenerative disease information to CDPH.

In an effort to provide data providers information about the neurodegenerative disease information CDPH will collect, via the CPDR and CNDR, this neurodegenerative disease guide to reporting was created. Please read the information provided within this neurodegenerative disease guide to reporting to become familiar with which diseases CPDR and CNDR will collect, how CDPH will collect neurodegenerative disease information, the information that is required to report or required to report if available, and the reporting deadlines.

CDPH has engaged partners, subject matter experts, and data providers since the inception of CPDR and through the development, implementation and disease expansion of CNDR to ensure the information provided in this neurodegenerative disease guide to reporting is current and up to date. CDPH will continue to engage those same groups to ensure the information collected is accurate, up to date, and is used for determining incidence and prevalence of neurodegenerative disease in California.

Please Note: Data providers currently reporting Parkinson's Disease and multiple sclerosis (MS) data to CDPH do not need to alter their current reporting process unless your facility is also treating patients with other reportable neurodegenerative disease such as MS and Alzheimer's disease.

2. Purpose

This neurodegenerative disease guide to reporting describes who is required to report, the reporting criteria, and the CPDR/CNDR reporting deadlines. The guide also defines the methods for reporting, including the supported methods for data transmission, and provides the necessary specifications for automated electronic reporting of data. In addition, the guide defines the specific data elements to be included in the neurodegenerative disease case reports; describes how to create the appropriate, valid electronic message for transmission; and details how to transmit the reports to CPDR/CNDR over a secure electronic transmission mechanism.

3. CPDR/CNDR Reporting Requirements

3.1. Who is Required to Report?

Licensed independent practitioners[1] (LIPs) holding the following credentials, who diagnose or treat neurodegenerative disease patients, **are required** to report: Doctor of Medicine (MD), Doctor of Osteopathy (DO), Physician's Assistant (PA), and Nurse Practitioner (NP). Other LIPs, including advanced practice registered nurses, home care nurses, physical/occupational/speech therapists, chiropractors, podiatrists, acupuncturists, and optometrists **are not required** to report. If LIPs work in a group practice, have a formalized relationship within the practice, or are part of a hospital or facility medical staff, the encounter reporting can be performed by the hospital or facility. A single report may constitute encounter data from multiple LIPs.

Please Note: Encounter as referenced in these sections means an interaction between a patient and LIPs providing diagnostic, treatment or therapeutic services for Parkinson's disease or a neurodegenerative disease.

3.2. Determination of Reportability

Patient encounters for diagnosis or treatment of Parkinson's Disease occurring on or after July 2018 or neurodegenerative disease(s)[2] occurring on or after July 1, 2023 are reportable to CPDR and CNDR respectively. Please note, historical backload reporting is **not required for either condition**. Patient encounters are reportable when(a) the patient has not been previously reported to the CPDR/CNDR or (b) the triggering reportable diagnosis resulted in a change to the medical record (either entering an initial diagnosis or change in diagnosis) during the encounter (See Figure 1). Please note, encounters are not reportable if the diagnosis is noted on the Problem List but is not applied to the encounter itself.

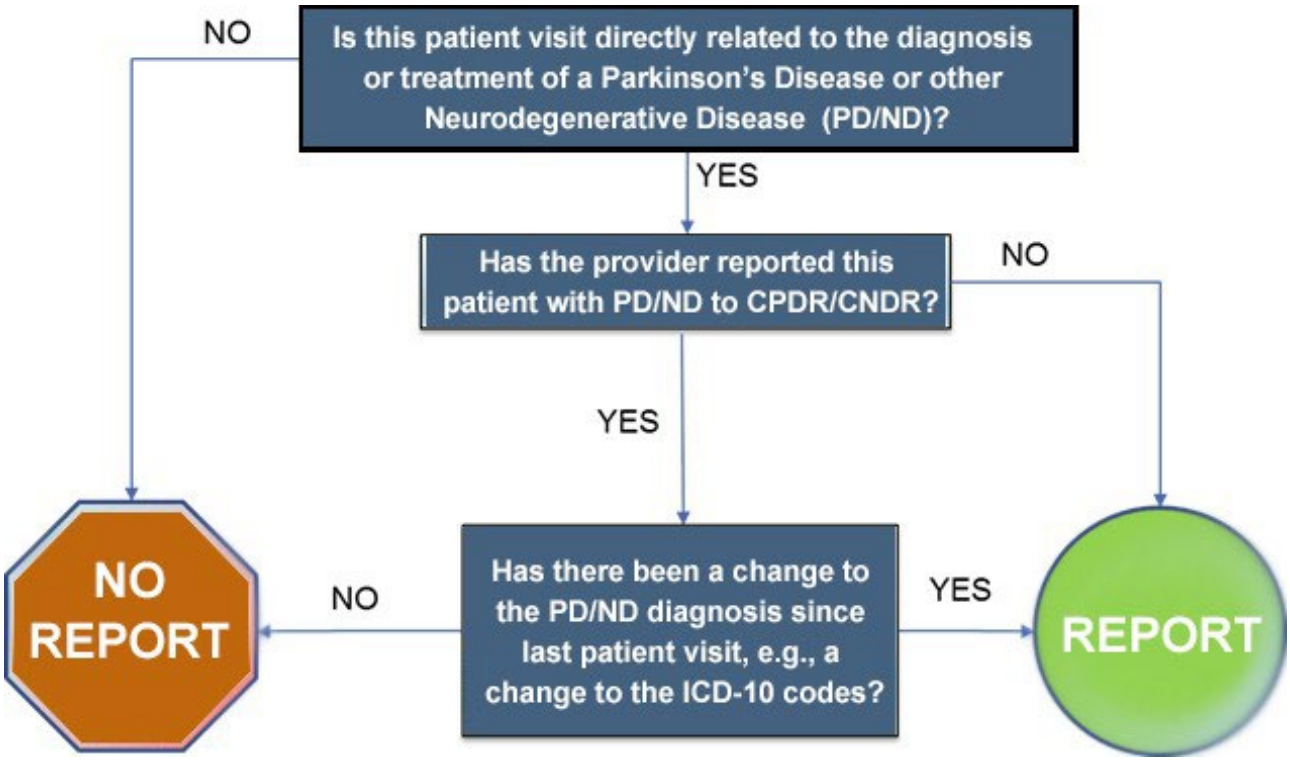
Any encounter type can trigger the requirement for reporting, including ambulatory visits, emergency department visits, inpatient hospital stays, non-acute institutional stays, and other outpatient visits. Reportable encounters also include face-to-face visits as well as certain non-face-to-face visits (telemedicine, telephone, online/e-visits) that include discussion about treatment or diagnosis of Parkinson's disease or other neurodegenerative diseases that are reportable to CPDR/CNDR. Inpatient encounters can rely on diagnostic coding done for

[1] As per the Joint Commission, licensed independent practitioner is defined as an individual permitted by California law and regulation, and by the organization, to provide care and services without direction or supervision within the scope of the individual's license and consistent with the privileges granted by the organization.

[2] "Neurodegenerative disease" may include, but is not limited to, Alzheimer's disease, multiple sclerosis (MS), Huntington's disease, and amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. CDPH will decide what specific neurodegenerative disease will be reportable.

hospital billing purposes to trigger reportability. However, ancillary encounters (e.g., imaging, cardio-pulmonary, and therapies) are excluded from reporting.

Figure 1. Flow chart of Reportable Parkinson's Disease and Reportable Neurodegenerative Disease Cases



As shown in Figure 1, Parkinson's disease and other neurodegenerative disease patients not previously reported are reportable regardless of the encounter. Subsequent encounters for a previously reported patient are only reportable if their visit results in a change in diagnosis that is recorded in their medical record (e.g., a change from ICD10 code G20.A1 to F03.918).

International Classification of Diseases, Tenth Revision (ICD-10) codes will be used to identify reportable cases of neurodegenerative diseases (See Table 1).

Table 1. ICD-10 Codes and Their Clinical Descriptions

ICD-10 Code	Description
Parkinson's Disease	
G20.A1	Parkinson's disease without dyskinesia, without mention of fluctuations
G20.A2	Parkinson's disease without dyskinesia, with fluctuations
G20.B1	Parkinson's disease with dyskinesia, without mention of fluctuations
G20.B2	Parkinson's disease with dyskinesia, with fluctuations
G20.C	Parkinsonism, unspecified
G90.3	Multi-system degenerative of the autonomic nervous system
Multiple Sclerosis	
G35	Multiple Sclerosis
G37.3	Acute transverse myelitis in demyelinating disease of central nervous system
G37.89	Other specified demyelinating diseases of central nervous system
G37.9	Demyelinating disease of central nervous system, unspecified
Alzheimer's Disease	
F01.50	Vascular dementia, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F01.A0	Vascular dementia, mild, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F01.B0	Vascular dementia, moderate, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F01.C0	Vascular dementia, severe, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F02.A0	Dementia in other diseases classified elsewhere, mild, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F02.B0	Dementia in other diseases classified elsewhere, mild moderate, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety

Table 1. ICD-10 Codes and Their Clinical Descriptions

ICD-10 Code	Description
F02.C0	Dementia in other diseases classified elsewhere, severe, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F02.80	Dementia in other diseases classified elsewhere, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F02.811	Dementia in other diseases classified elsewhere, unspecified severity, with agitation
F02.818	Dementia in other diseases classified elsewhere, unspecified severity, with other behavioral disturbance
F03.90	Unspecified dementia, unspecified severity, without behavioral disturbance, psychotic disturbance, mood disturbance, and anxiety
F03.911	Unspecified dementia, unspecified severity, with agitation
F03.918	Unspecified dementia, unspecified severity, with other behavioral disturbance
G30.0	Alzheimer's disease with early onset
G30.1	Alzheimer's disease with late onset
G30.8	Other Alzheimer's disease
G30.9	Alzheimer's disease, unspecified
G31.83	Neurocognitive disorder with Lewy bodies
G31.09	Other frontotemporal neurocognitive disorder

3.3. What is Reportable?

Reportable data elements are identified in *Appendix 1. Table of Data Elements for Manual Reporting to the CPDR/CNDR* and *Appendix 2. Table of Data Elements for Electronic Reporting to the CPDR/CNDR*.

3.4. Timing of Reporting

Regardless of the reporting modality (i.e., manual entry via web portal or submission via electronic interface) timing of reporting is based on the calendar quarter during which the encounter occurred. For the first quarter of the mandate (i.e., patient encounters occurring between July 1 and September 30) encounters must be reported within 180 days following the end of the quarter

(i.e., March 31, for reporting between July 1, and September). Beginning October 1st, the deadline for data submission is 90 days following the end of the quarter. Frequency of data submission may be determined by the reporting physician or facility, but all data must be received by the deadlines outlined below (See Table 2). For inpatient encounters, the discharge date may be used as the date of the encounter.

Table 2. Data Collection Timeframe and Case Submission Deadlines

Date of Patient Encounter*	Submission Deadline (Is the last day of each month)
July – September	December **
October – December	March
January – March	June
April – June	September

*For inpatient settings, the discharge date may be used as the date of the patient encounter.
The first reporting period (July-September) **has a six-month deadline (i.e., data is due to the CNDR by March 31); All subsequent reporting periods have **three-month deadlines**.

4. Technical Implementation

4.1. Methods for Reporting

CPDR/CNDR will accept electronic case reports through two primary methods of reporting: (1) manual data entry via Direct Data Entry Web Portal (secure web page accessible only to registered providers, facilities, and hospitals) and (2) automated electronic transfer of case files from the provider's electronic medical record system.

1. Manual Data Entry (via Direct Data Entry Web Portal)

A Direct Data Entry Web Portal will be provided to physicians, facilities, and hospitals who do not have the ability to output and send an electronic message to CPDR/CNDR. The Direct Data Entry Web Portal will support the manual entry of 'required' and 'required if available' data fields. Registrants for the CPDR/CNDR are only required to fill out fields highlighted in red. Fields for phone numbers, emails, and marital status are to be left blank. Information for these fields is not collected by CPDR/CNDR. The Direct Data Entry Web Portal will require manual input of data fields for each patient and may not be the most efficient solution for physicians or facilities that diagnose and treat a moderate to high volume of patients.

2. Automated Electronic Transfer of Case Files (via Electronic Interface)

CPDR/CNDR is also establishing a secure system that healthcare providers can use to automate neurodegenerative disease case reporting. With the advancement of health information technology, patient data can be exchanged efficiently between reporting entities (providers, hospitals, and other facilities) and the CPDR/CNDR using Health Level Seven (HL7) format standards. Using this method, information from the patient's electronic medical record is transmitted to the CPDR/CNDR without the reporting entity needing to manually enter data into a web portal.

CPDR/CNDR will support two versions of HL7:

1. HL7 CDA R2 Implementation Guide: Public Health Case Report, Release 2 STU 1.1 – US Realm
    a. See Neurodegenerative Disease Registry HL7 CDA eICR Data Elements
2. HL7 2.5.1 ORU_R01 based specification standard. [See *CPDR/CNDR, Electronic Reporting of Neurodegenerative Disease*
    a. See California Neurodegenerative Disease Registry HL7 251 Constraints v1

The reporting system is secured using state approved information security standards and will ease the burden of reporting for those providers and facilities willing and able to leverage the technology.

4.2. Data Elements

For either method of reporting, all data elements listed in Appendix 1 and Appendix 2 are required or required if available. If a data element is required it must be transmitted with a value other than empty, blank, or null, or the record will not be accepted. For a data element that is required if available it must be sent when a known value is available in the sending system. However, if a data element has an allowable code for "unknown" then that code should be transmitted for that element instead of an empty value.

4.3. Transmission Methods

As previously noted, CPDR/CNDR will accept electronic case reports through the two methods of transmission: manual data entry via Direct Data Entry Web Portal or automated electronic transfer of case files. The following methods of transmission are supported for the automated electronic transfer of case files:

4.3.1. Secure File Transfer Protocol (SFTP)

4.3.2. Web Services – Simple Object Access Protocol (SOAP 1.2)

4.4. On-boarding

Provider Registration: For either method of reporting, reporting entities (providers, facilities, and hospitals) can establish their intent to report by emailing us at cdsrbhelp@cdph.ca.gov to start the registration process. The reporting requirement falls on the entity that will complete reporting. Thus, if an individual LIP will report their own cases, the LIP should register. However, if the facility or hospital will report for their affiliated LIPs, only the facility or hospital should register. Registering is voluntary for those submitting through the interface; however, registration will assist in management of the onboarding process and document intent to report.

Data Submission Testing/Validation: Providers wishing to use the electronic interface for reporting will work with CPDR/CNDR in a data submission testing and validation phase to initiate connectivity, validate message structure, validate content, and perform user acceptance testing. Upon validation, data submission will transition to production reporting.

Step 1. Initiate Connectivity

4.4.1. Work with CPDR/CNDR staff to establish connectivity (using SOAP transport method or SFTP).

Step 2. Validate Message Structure:

4.4.2. Implement logical filters to ensure that only reportable neurodegenerative disease cases are sent to CPDR/CNDR.

Ensure that the information system produces a message compliant with CPDR/CNDR HL7 CDA R2 Implementation Guide: Public Health Case Report, Release 2 STU 1.1 – US Realm or CPDR/CNDR HL7 2.5.1 ORU_R01.

4.4.3. Perform structural testing of messages without Protected Health Information (PHI)

Step 3. Validate Content and Acceptance Testing:

4.4.4. Work with CPDR/CNDR staff to ensure that message content is valid and logical filters are properly formatted and functioning to send complete reportable cases.

Step 4. Transition to Production:

4.4.5. Upon successful completion of User Acceptance Testing (UAT), a submitter's CPDR/CNDR feed will transition to production reporting. This marks the transition to CDPH and CPDR/CNDR ongoing support.

Following the successful completion of the testing and validation phase, providers will be required to consistently submit production data.

5. Ongoing Data Validation

After completing initial implementation validation, data quality will continue to be monitored by CPDR/CNDR. If data quality changes after passing validation CPDR/CNDR will notify and work with facilities or providers to improve data quality for neurodegenerative disease surveillance.

6. Support

For questions regarding establishing connectivity with the registry, or for ongoing support. Please email us at cdsrbhelp@cdph.ca.gov.

Appendix 1. Table of Data Elements for Manual Reporting to the CPDR/CNDR

Data Content Area	Requirement Optionality[1]	Field
Patient ID	R	Name (Last, First, MI)
	R	Date of Birth
	R	Sex - (Gender)
	R	Patient Street Address (Street & No)
	R	Patient Address City
	R	Patient Address State
	R	Patient Address Zip (Postal) Code
	RE	Social Security Number
	R	Medical Record Number - MRN
Patient Demographics	R	Race
	R	Ethnicity
	RE	Date Last Contact/Death
	RE	Sexual Orientation
	RE	Gender Identity
Patient Visit Information	RE	Attending Doctor
	RE	Consulting Doctor
	RE	Hospital Service
	RE	Admission Reason
Physician Identifiers (Primary)	R	Physician Name (Last, First)
	R	Author NPI - Physician ID
	R	Physician Specialty
	R	Physician Address (Street & No)
	R	Physician Address State
	R	Physician Address Zip (Postal) Code
	R	Physician email
	R	Physician License Number

[1]R = Required, RE = Required if available

[2]Date of Diagnosis is RE if the case was diagnosed before July 1, 2018, R if diagnosed after 7/1/18; transmission of the date that a triggering diagnosis was first documented on the patient's Problem List in the practitioner's electronic health record system is acceptable.

Appendix 1. Table of Data Elements for Manual Reporting to the CPDR/CNDR

Data Content Area	Requirement Optionality[1]	Field
Primary Diagnosis	R	ICD-10/Diagnostic Term
	R	Month and/or Year of Diagnosis[2]
Disease Onset	RE	Onset Date, Onset of Symptoms, if known
	RE	Symptoms at Onset

[1]R = Required, RE = Required if available

[2]Date of Diagnosis is RE if the case was diagnosed before July 1, 2018, R if diagnosed after 7/1/18; transmission of the date that a triggering diagnosis was first documented on the patient's Problem List in the practitioner's electronic health record system is acceptable.

Appendix 2. Table of Data Elements for Electronic Reporting to the CPDR/CNDR

Data Content Area	Requirement Optionality[1]	Field
Facility ID	R	Reporting Facility Name
	R	Reporting Facility ID
	R	Facility Address
	R	Facility Phone Number
	R	Sending Facility Application
	R	Date/Time of Message
	RE	Facility Type
Software ID	R	Software Vendor Organization
	R	Software Version or Release Number
	R	Software Product Name
	R	Software Binary ID
Patient ID	R	Name (Last, First, MI)
	R	Date of Birth
	R	Sex - (Gender)
	R	Patient Street Address (Street & No)
	R	Patient Address City
	R	Patient Address State
	R	Patient Address Zip (Postal) Code
	RE	Social Security Number
	R	Medical Record Number - MRN

[1] R = Required, RE = Required if available

[2] Date of Diagnosis is RE if the case was diagnosed before July 1, 2018, R if diagnosed after 7/1/18; transmission of the date that a triggering diagnosis was first documented on the patient's Problem List in the practitioner's electronic health record system is acceptable.

Appendix 2. Table of Data Elements for Electronic Reporting to the CPDR/CNDR

Data Content Area	Requirement Optionality[1]	Field
Patient Demographics	R	Race
	R	Ethnicity
	RE	Date Last Contact/Death
	RE	Sexual Orientation
	RE	Gender Identity
Patient Visit Information	RE	Attending Doctor
	RE	Consulting Doctor
	RE	Hospital Service
	RE	Admission Reason
Physician Identifiers (Primary)	R	Author NPI - Physician ID
	R	Physician office phone number
Primary Diagnosis	R	ICD-10/Diagnostic Term
	R	Month and/or Year of Diagnosis[2]
	RE	Comment
Disease Onset	RE	Onset Date, Onset of Symptoms, if known
	RE	Comment

[1] R = Required, RE = Required if available

[2] Date of Diagnosis is RE if the case was diagnosed before July 1, 2018, R if diagnosed after 7/1/18; transmission of the date that a triggering diagnosis was first documented on the patient's Problem List in the practitioner's electronic health record system is acceptable.