The California Parkinson's Disease Registry

Implementation Guide

California Department of Public Health
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1. Introduction

California State Senate Bill (SB) 97, signed by Governor Jerry Brown in July 2017, established the Richard Paul Hemann Parkinson's Disease Program, updating the California Health and Safety Code (HSC) [103860-103870] regarding the reporting of Parkinson's disease. Beginning July 1, 2018, health care providers diagnosing or providing treatment to Parkinson's disease patients will be required to report each case of Parkinson's disease to the California Department of Public Health (CDPH). This implementation guide provides the information needed to meet this new reporting mandate.

2. Purpose

This Implementation Guide outlines who is required to report, the reporting criteria, and the timing of reporting to the California Parkinson's Disease Registry (CPDR). The guide defines the methods for reporting, the supported methods for data transmission, and provides the necessary specifications for reporting of data to CPDR. In addition, the guide defines the specific data elements to be included in the Parkinson's disease case reports; describes how to create the appropriate, valid electronic message for transmission; and details how to transmit the reports to CPDR over a secure electronic transmission mechanism.

3. CPDR Reporting Requirements

3.1. Who is Required to Report, and When?

SB 97 requires that beginning July 1, 2018, hospitals, facilities, physicians and surgeons, or other healthcare providers diagnosing or providing treatment to Parkinson's disease patients must report each case of Parkinson's disease to CDPH.

3.2. Determination of Reportable Cases

The International Classification of Diseases, Tenth Revision (ICD-10) codes will be used to identify reportable cases of Parkinson's disease. All patient interactions involving one or more ICD-10 codes provided below (see Table 1) are reportable except when <u>both</u> of the following conditions apply:

a. The provider has previously reported on the patient, and
b. There are no changes to diagnosis, treatment, or cardinal signs/symptoms of Parkinson's disease since the last report on that patient.

Table 1. Reportable ICD-10 Codes and Their Clinical Descriptions

ICD-10 Code	Description
G20***	Parkinson's disease/Parkinsonism
G3183	Dementia with Lewy bodies (DLB)
G90.3	Parkinsonism with neurogenic orthostatic hypotensions, Multiple system atrophy (MSA), MSA-Parkinson (MSA-P), MSA-Cerebella (MSA-C)
G231 and G232	Other degenerative diseases of the basal ganglia (PSP and Striatonigral degeneration)
G3185	Corticobasal degeneration

Note: G20*** refers to the primary code of G20 and any other specificity.

3.3. What is Reportable?

Reportable data elements are identified in *Appendix 1. Table of Data Elements for Electronic Reporting to the California Parkinson's Disease Registry.*

3.4. Timing of Reporting

Cases of Parkinson's disease will be required to be reported within 90 days of patient contact. Automated data submissions (discussed in detail below) from reporting facilities must occur at least on a quarterly basis.

4. Technical Implementation

4.1. Methods for Reporting

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

Manual Data Entry (via Direct Data Entry Web Portal):

A Direct Data Entry Web Portal will be provided for physicians who do not have the ability to output and send an electronic message to CPDR. The Direct Data Entry Web Portal will support direct entry of 'required' and 'required if available' data fields. The Direct Data Entry Web Portal will require manual input of data fields and may not be the most efficient solution for physicians or facilities who diagnose and treat a moderate to high volume of patients.

Automated Electronic Transfer of Case Files (via Electronic Interface)

CPDR is also establishing a secure system that healthcare providers can use to automate Parkinson's disease case reporting. With the advancement of technology in the healthcare environment, healthcare data can be exchanged efficiently between providers and CPDR using Health Level Seven (HL7) version 2 format standards. Using this method, information from the patient's electronic medical record is transmitted to CPDR without the physician needing to re-enter into a web portal. CPDR has developed an HL7 ORU R01 based specification that providers can use to efficiently transmit case data. [See *California Parkinson's Disease Registry, Electronic Reporting of Parkinson's Disease* (http://www.cdph.ca.gov/parkinsons)]. The system is secured using state approved 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. Table of Data Elements for Electronic Reporting to the California Parkinson's Disease Registry* are required or required if accessible. 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. 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. Data Format

For either reporting method, CPDR is limiting the formatting of Parkinson's disease reports to the following options:

- Structured using Unified Parkinson's Disease Rating Scale (UPDRS)
- Narrative

If a provider does not utilize UPDRS, then submission of case data using the narrative format is acceptable. However, if a facility currently supports UPDRS, submissions utilizing UPDRS are supported.

4.4. Transmission Methods

As previously noted, CPDR 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:

- Secure File Transfer Protocol (SFTP)
- Web Services – Simple Object Access Protocol (SOAP 1.2)

4.5. On-boarding

Provider Registration

For either method of reporting, providers will need to first establish their intent to report by registering their provider information on the CDPH Health Information Exchange (HIE) Gateway, beginning in June 2018 (https://hie.cdph.ca.gov/).

For manual data entry, CPDR will be using the registration list to subsequently work with providers to establish an account on the Direct Data Entry Web Portal. The Direct Data Entry Web Portal will be a secured website conforming to state level security requirements for the data entry of confidential patient information to CPDR.

Upon successful registration for the automated process, SFTP login information and/or a SOAP 1.2 web interface implementation guide will be provided. If providers would like to work with CPDR on configuration for reporting prior to availability of the registration portal, please contact CPDR at CPDRhelp@cdph.ca.gov.

Data Submission Testing/Validation

Providers pursuing the electronic interface for reporting will be working with CPDR 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

- Work with CPDR staff to establish connectivity using SOAP transport method.

Step 2. Validate Message Structure:

- Construct logical filters to ensure that only reportable Parkinson's disease cases are sent to CPDR.
- Ensure that the information system produces a message compliant with CPDR HL7 version 2.5.1.
- Perform structural testing for messages without Protected Health Information (PHI) using the developer tool: web validator.

Step 3. Validate Content and Acceptance Testing:

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

Step 4. Transition to Production:

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

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

5. Ongoing Data Evaluation Plan

After passing validation, data quality will continue to be monitored by CPDR. If data quality changes after passing validation, CPDR will notify and work with facilities or providers to improve data quality for Parkinson's disease surveillance.

Appendix 1. Table of Data Elements for Electronic Reporting to the California Parkinson's Disease Registry

Data Content Area	Requirement Optionality[1]	Field	HL7 Segment/Sequence
Facility ID	R	Reporting Facility Name	MSH.3, ORC.21
	R	Reporting Facility ID	MSH.4
	R	Facility Address	ORC.22
	R	Facility Phone Number	ORC.23
	R	Sending Facility Application	MSH.3
	R	Date/Time of Message	MSH.7
	RE	Facility Type	PV1.10
Software ID	R	Software Vendor Organization	SFT.1
	R	Software Version or Release Number	SFT.2
	R	Software Product Name	SFT.3
	R	Software Binary ID	SFT.4
Patient ID	R	Name (Last, First, MI)	PID.5
	R	Date of Birth	PID.7
	R	Sex - (Gender)	PID.8
	RE	Phone Number	PID.13
	RE	Email Address	PID.15
	R	Patient Street Address (Street & No)	PID.11
	R	Patient Address City	PID.11
	R	Patient Address State	PID.11
	R	Patient Address Zip (Postal) Code	PID.11
	RE	Social Security Number	PID.19
	R	Medical Record Number - MRN	PID.3
Patient Demographics	R	Race	PID.10
	R	Ethnicity	PID.22
	RE	Marital Status	PID.16
	RE	Religion	PID.17
	RE	Date Last Contact/Death	PID.29
Next of Kin	RE	Name (Last, First, MI)	NK.2
	RE	Relationship	NK.3
	RE	Address	NK.4, NK.32
	RE	Phone Number	NK.5, NK.31

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

Data Content Area	Requirement Optionality[1]	Field	HL7 Segment/Sequence
Patient Visit Information	RE	Attending Doctor	PV1.7
	RE	Referring Doctor	PV1.8
	RE	Consulting Doctor	PV1.9
	RE	Hospital Service	PV1.10
	RE	Date/Time Patient Arrived for Services	PV1.44
	RE	Date/Time Patient services ended	PV1.45
	RE	Admission Reason	PV2.3
Physician Identifiers (Primary)	R	Author NPI - Physician ID	OBR.16
	R	Physician phone number	OBR.17
Primary Diagnosis	R	ICD-10/Diagnostic Term	OBX.5 following Diagnosis OBR
	R	Month/Year of Diagnosis	OBX.14
	R	Comment	Optional NTE segment following Primary Diagnosis OBX
Secondary Diagnosis	RE	Comorbid Condition(s)	OBX.5 following Diagnosis OBR
	RE	Comment	Optional NTE segment following Secondary Diagnosis OBX
Disease Onset	RE	Onset Date, Onset of Symptoms	OBX.5 following Diagnosis OBR
	RE	Comment	Optional NTE segment following Disease Onset OBX

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

Data Content Area	Requirement Optionality[1]	Field	HL7 Segment/Sequence
Cardinal Signs / Symptoms of PD	RE	UPDRS: Mentation, Behavior, Mood	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Activities of Daily Living	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Motor Examination	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Complications of Therapy	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Hoen and Yahr Staging	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Schwab England Activities of Daily Living	OBX.5 following the Cardinal Signs Order OBR
	RE	UPDRS: Schwab England: with Dyskinesia	OBX.5 following the Cardinal Signs Order OBR
	RE	Clinical notes regarding general cardinal signs and/or symptoms of Parkinson's disease	Optional NTE segment following Cardinal Signs OBX
Surgical Treatments	RE	Deep Brain Stimulation, Neuroablative Procedures	OBX.5 following Surgical Treatments Order OBR
	RE	Comments	Optional NTE segment following Surgical Treatments OBX
Medications	RE	Name	OBX.5 following Medication Order
(fields may repeat, Med 1, Med 2,…..)	RE	Identifier	OBX.5 following Medication Order
	RE	Dose	OBX.5 following Medication Order
	RE	Frequency	OBX.5 following Medication Order
	RE	Comments	Optional NTE Segment following Medications OBX

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