

The South Carolina Parkinson's Disease Registry

Guide to Reporting

1. Introduction

The South Carolina Parkinson's Disease Research Collection Act was signed into legislation on May 23, 2022. This act went into effect on June 1, 2023 and the Medical University of South Carolina was designated as the establishing body. There is a mandated registry that all newly and previously diagnosed cases of Parkinsons Disease and Parkinsonism's will need to be submitted to. The list of eligible ICD-10 codes in the reporting requirements section. The Research collection act also established the development of Parkinsons Disease research registry for the state of SC. The research registry is not mandated but all patients must be informed of the opportunity to participate per the law. Patients will have the opportunity to opt out of having extra data collected and shared with the research database. MUSC will be working on developing a solution to this need that puts as little burden as possible on the reporting physicians and patients.

2. Purpose

The primary goal of the statewide Parkinson's disease population-based registry is to produce more accurate estimates of the incidence and prevalence of disease in the state. The establishment of the research database will support epidemiological and clinical research and public health surveillance. The South Carolina Parkinson's disease registry will be collecting comprehensive data that specifically focuses on determining incidence and prevalence more accurately, improving the lives of people affected by Parkinson's.

3. Reporting Requirements

Reporting will occur when a patient has one of the eligible ICD-10 codes in their EHR. At the time of the patients first encounter after the registry's establishment at your institution the eligible patient will be added to the mandated registry. Encounters that can trigger a reporting requirement for physicians in South Carolina includes emergency department visits, inpatient hospital stays, and other outpatient visits. Encounters are reportable when a new Parkinson's or Parkinsonism diagnosis is made or when patient that has an existing diagnosis but has not yet been added to the registry. Reporting entities that use Epic will have automated process for the mandated dataset, those who do not use Epic may be able to establish an automated transfer process with MUSC or will need to use a REDCap survey for data entry.

Eligible ICD-10 Codes

Patients with one of the ICD-10 codes listed below will need to be submitted to the **mandated** SC Parkinsons Registry and informed of their opportunity to participate in the SC Parkinsons research database.

ICD-10 Code	Description
G20	Parkinson's disease
G20.A1	unspecified fluctuations without dyskinesia
G20.A2	with fluctuations without dyskinesia
G20.B	Parkinson's disease with dyskinesia
G20.B1	Parkinson's disease with dyskinesia without fluctuations
G20.B2	Parkinson's disease with dyskinesia with fluctuations
G20.C	Parkinsonism unspecified
G21	Secondary Parkinsonism
G21.1	Other Drug-induced secondary parkinsonism
G21.2	Secondary parkinsonism due to other external agents
G21.3	Postencephalitic Parkinsonism
G21.4	Vascular Parkinsonism
G21.8	Other Secondary Parkinsonism
G21.9	Secondary Parkinsonism, Unspecified
G21.11	Neuroleptic induced parkinsonism
G21.19	Other drug induced secondary parkinsonism.
G23.1	Progressive supranuclear ophthalmoplegia
G23.2	Striatonigral degeneration
G31.83	Neurocognitive Disorder with Lewy Bodies
G31.85	Corticobasal degeneration
G90.3	Multi-system degeneration of the autonomic nervous system