

CPDR Data Flow



Data Submission

- Data are received from health care facilities.
- Automated via Electronic Health Record or manually via CalREDIE.



Quality Control

- Data are quality controlled for reporting criteria defined in the *CPDR Guide to Reporting*.
- Facilities receive data quality reports for their submissions.



Deduplication

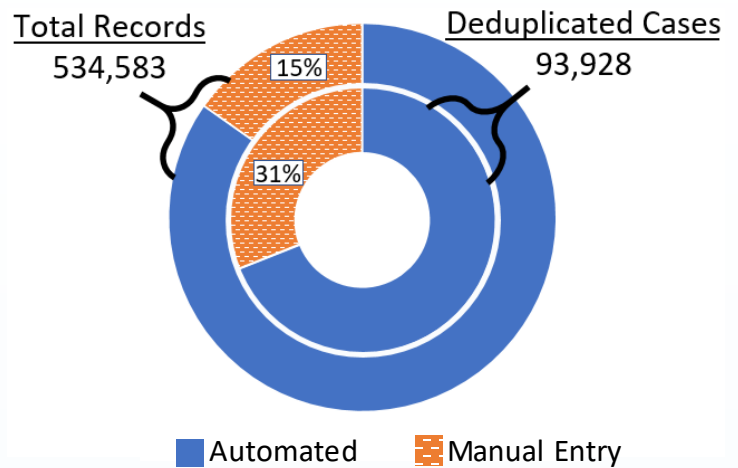
- Data are deduplicated and consolidated for research.
- Data will be linked with external sources for data improvement.



Data Use and Disclosure

- The policies and procedures for CPDR data release are now available on our website.
- Data are used to estimate Parkinson's disease incidence and prevalence in California.

Data Submission Summary



Among the total records submitted, automated entries outnumber manual entries by a ratio of about 6:1 (outer ring). After deduplication, cases submitted manually account for about one-third of the unique cases (inner ring).

The table below summarizes the total records, unique facilities, and unique patients for each entry method.

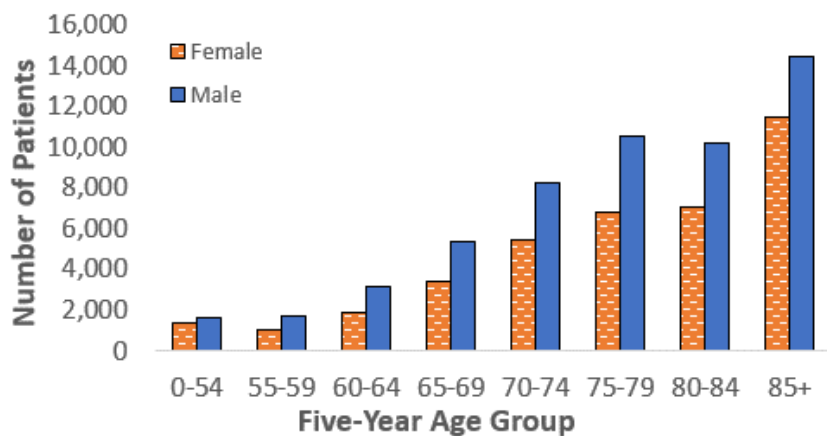
Entry Method	Records	Facilities	Patients
Automated	453,192	215	64,571
Manual Entry	81,391	335	29,357
Total:	534,583	550	93,928

Registry and Reporting Highlights

- As of December 31, 2021, CPDR received **534,583 total records** from 550 reporting entities, representing approximately **93,928** unique Parkinson's patients in California.
 - CPDR continues to onboard health facilities, process data, and increase data capture.
- Records submitted automatically continue to outnumber those submitted manually, although both reporting methods contribute a substantial amount of patient data to CPDR.
- Data has been successfully collected through the first three and a half years of mandated reporting, which began on July 1, 2018.
- Assembly Bill 133 (Chaptered July 11, 2021) has extended the California Parkinson's Disease Registry indefinitely.



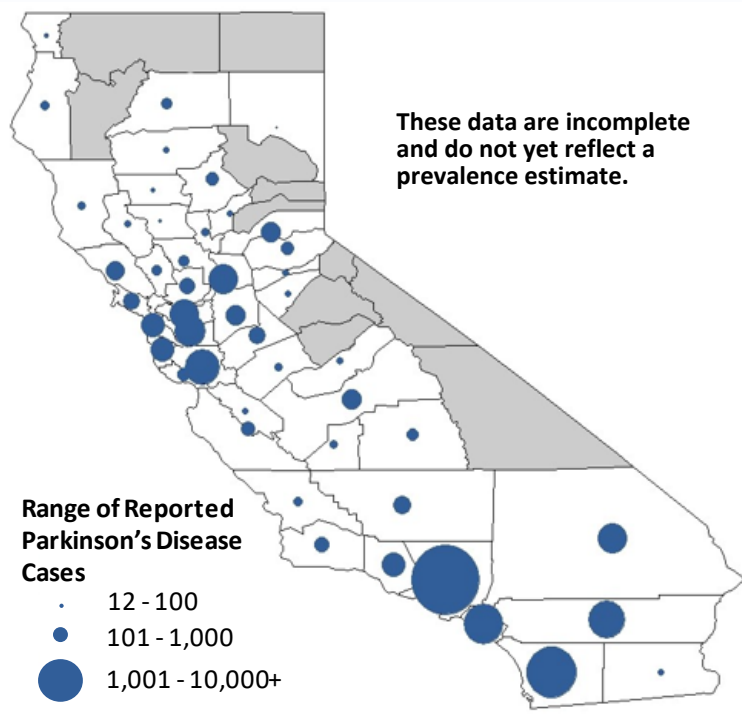
Parkinson's Cases by Age and Gender



- Among the patients currently in the registry, the number of patients **under the age of 55 years is 2,983 (3 percent)**. The number of patients **over the age of 85 years is 25,984 (27 percent)**, reflecting the age-related increase in Parkinson's risk.
- Based on data as of December 31, 2021, CPDR data show a male-to-female ratio of **approximately 1.5:1** or **almost a 50 percent greater likelihood** of Parkinson's disease occurring in males within the current sample of data.

Gender	0-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
Female	1,337	1,040	1,874	3,388	5,482	6,779	7,115	11,520
Male	1,646	1,691	3,161	5,404	8,238	10,515	10,213	14,464

Reported Parkinson's Cases by County



Some counties have been omitted for de-identification purposes.

Demographics of Parkinson's Patients*

Sex

Characteristic	Count (N)	Percent (%)
Male	55,332	59.1
Female	38,535	40.8
Other/Unknown	61	0.1

Race

Characteristic	Count (N)	Percent (%)
White	58,013	61.8
Asian	8,405	8.6
Black or African American	3,149	3.3
American Indian or Alaska Native	640	0.7
Native Hawaiian or Other Pacific Islander	321	0.3
Other/Unknown	23,760	25.3

Ethnicity

Characteristic	Count (N)	Percent (%)
Not Hispanic or Latino	64,155	68.3
Hispanic or Latino	11,741	12.5
Unknown	18,032	19.2

*Does not account for misdiagnosis or completeness



Program Highlights and Next Steps

- CPDR has published and implemented a data disclosure protocol which allows qualified researchers with a valid scientific interest to apply for CPDR data.
- CPDR continues to improve the completeness and quality of registry data, including race-ethnicity, and develop estimates of statewide Parkinson's disease incidence and prevalence.
- Despite incomplete reporting, data from CPDR recapitulates previous epidemiological findings of increased Parkinson's disease risk among men and with increasing age.

Source: California Parkinson's Disease Registry (December 31, 2021).