



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

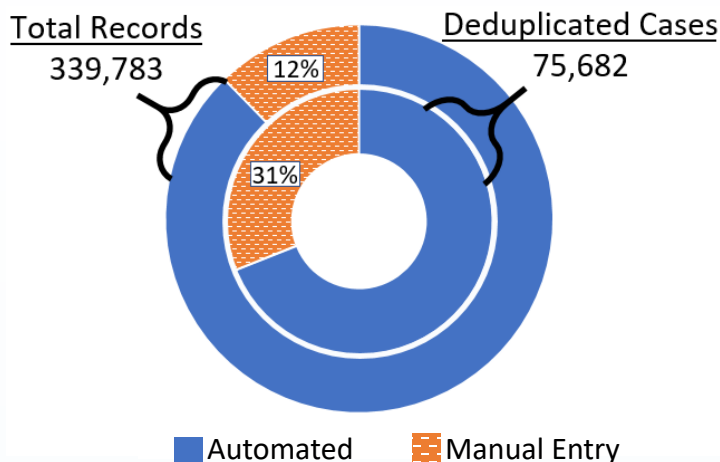


Data Use and Disclosure

- Data will be used to estimate Parkinson's disease incidence and prevalence in California.
- Data will be disclosed to qualified researchers for broader research.



Data Submission Summary



Among the total records submitted, automated entries outnumber manual entries by a ratio of about 8:1 (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	298,300	214	52,219
Manual Entry	41,483	324	23,463
Total:	339,783	538	75,682



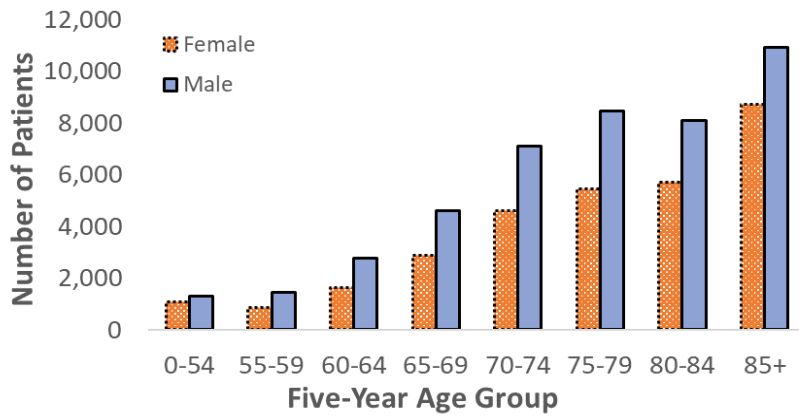
Registry and Reporting Highlights

- Data has been successfully collected through the first two and a half years of mandated reporting, which began on July 1, 2018.
- Assembly Bill 2821 has extended Parkinson's disease reporting until January 1, 2022.
- As of December 31, 2020, CPDR received **339,783 total records** from more than 500 reporting entities.
- From the total records submitted, CPDR has counted **75,682** Parkinson's patients in California.
 - CPDR continues to process data, increase data capture, and develop estimates of statewide Parkinson's disease incidence and prevalence.
- Records submitted automatically continue to outnumber those submitted manually, although both reporting methods contribute a substantial amount of patient data to CPDR.

Source: California Parkinson's Disease Registry (December 31, 2020).



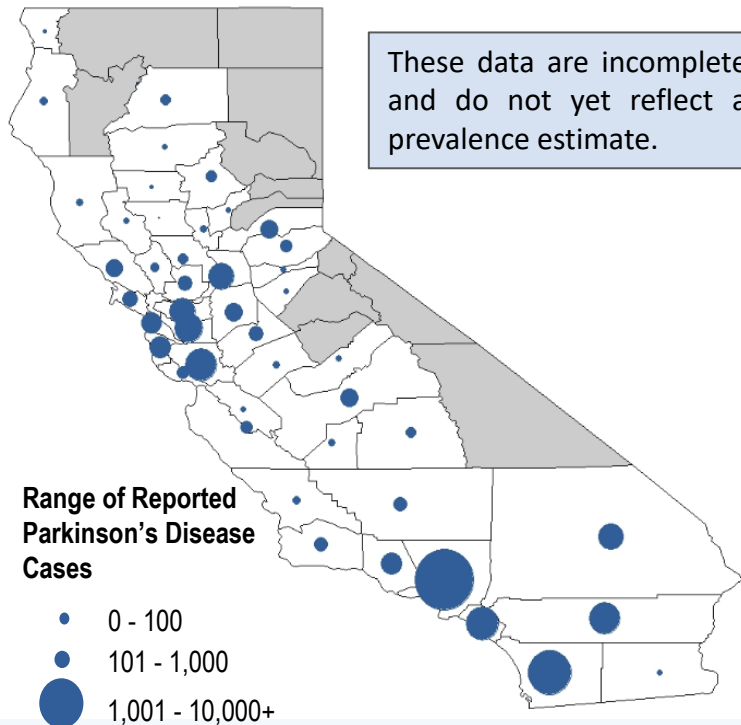
Parkinson's Cases by Age and Gender



- Among the patients currently in the registry, the number of patients **under the age of 55 years is 2,377**. The number of patients **over the age of 85 years is 19,622**, reflecting the age-related increase in Parkinson's risk.
- Based on data as of December 31, 2020, 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	1,077	860	1,641	2,870	4,610	5,445	5,691	8,716
Male	1,300	1,451	2,777	4,606	7,111	8,475	8,101	10,906

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	44,727	59.09
Female	30,910	40.84
Other/Unknown	45	0.06

Race

Characteristic	Count (N)	Percent (%)
White	47,140	62.29
Asian	6,548	8.65
Black or African American	2,488	3.29
American Indian or Alaska Native	465	0.61
Native Hawaiian or Other Pacific Islander	259	0.34
Other/Unknown	18,782	19.88

Ethnicity

Characteristic	Count (N)	Percent (%)
Not Hispanic or Latino	52,344	69.16
Hispanic or Latino	9,308	12.30
Unknown	14,030	18.54

*Does not account for misdiagnosis or completeness



Conclusions and Next Steps

- CPDR continues to onboard health facilities and improve data validation in order to increase the completeness and quality of registry data.
- Despite incomplete reporting, data from CPDR recapitulates previous epidemiological findings of increased Parkinson's disease risk among men and with increasing age.
- CPDR will publish and implement a data disclosure protocol which will allow qualified researchers with a valid scientific interest to apply for CPDR data.

Source: California Parkinson's Disease Registry (December 31, 2020).