



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*
- CPDR collects ICD-10 codes: G20, G90.3



Deduplication

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

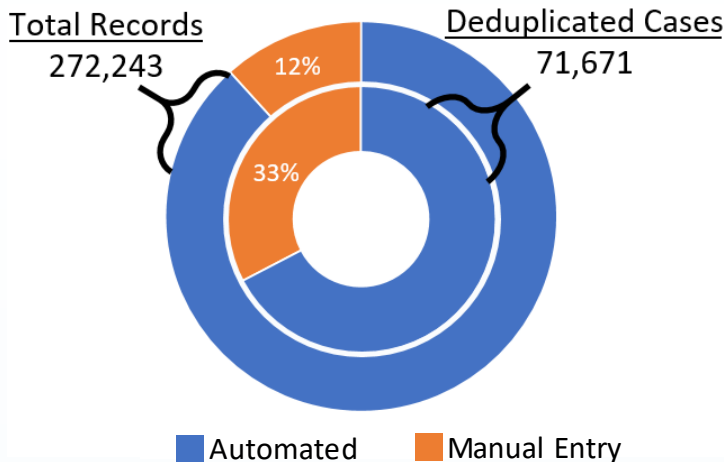


Data Use and Disclosure

- 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, case 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	240,366	212	48,238
Manual Entry	31,877	318	23,433
Total:	272,243	530	71,671

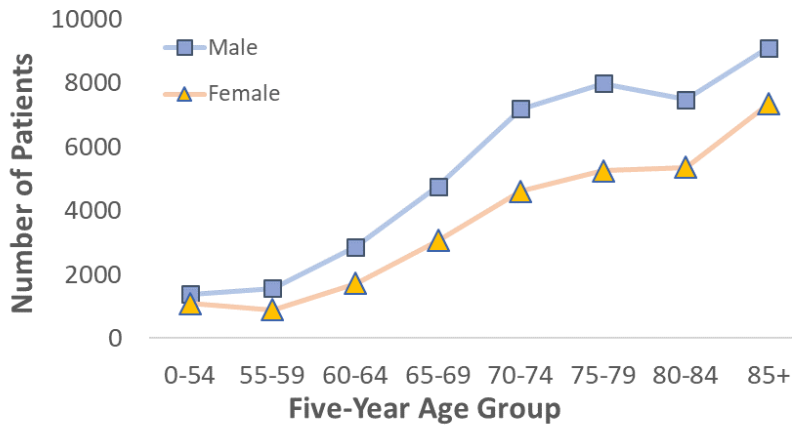


Registry and Reporting Highlights

- Data has been successfully collected through the first two years of mandated reporting which began on July 1, 2018 and extends until January 1, 2021.
- As of May 31, 2020, CPDR received **272,243 total records** from over 500 reporting entities.
- From the total records submitted, CPDR has counted **71,671** 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.
 - Among the unique patients submitted via automated entry, 4,930 or about 10% of these patients were also submitted through the manual method.
 - Conversely, 4,244 of the unique manually-submitted cases (18%) were also submitted via the automated method.



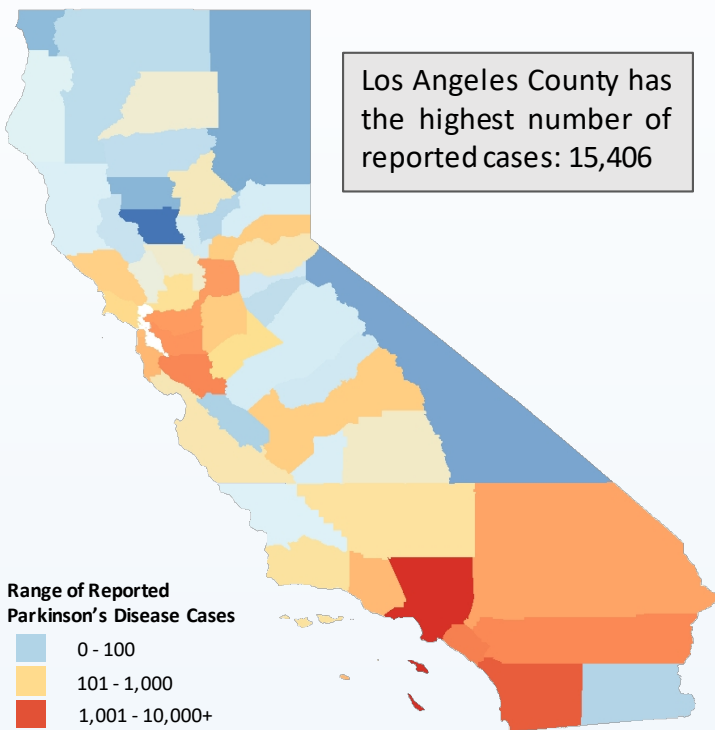
Parkinson's Cases by Age and Gender



- Among the patients currently in the registry, the number of patients **under the age of 55 years is 2,456**; The number of patients **over the age of 85 years is 16,450**, demonstrating the age-related increase in Parkinson's risk.
- Based on data as of May 31, 2020, CPDR estimates a male-to-female ratio of **approximately 1.5:1** or **almost a 50% greater likelihood** of Parkinson's disease occurring in males within the current sample of data.

	0-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
Male	1,373	1,568	2,864	4,759	7,189	7,983	7,484	9,106
Female	1,083	893	1,713	3,059	4,605	5,253	5,357	7,344

Reported Parkinson's Cases by County



Some counties have been combined for de-identification

Demographics of Parkinson's Patients*

Characteristic	Count (N)	Percent (%)
Sex		
Male	42,326	59.05
Female	29,307	40.89
Other/Unknown	38	0.05
Race		
White	44,655	62.31
Asian	6,176	8.62
Black or African American	2,340	3.26
American Indian or Alaska Native	447	0.62
Native Hawaiian or Other Pacific Islander	246	0.34
Other/Unknown	17,807	24.84
Ethnicity		
Not Hispanic or Latino	49,534	69.11
Hispanic or Latino	8,886	12.40
Unknown	13,251	18.49

* 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.
 - The data presented here are incomplete and do not reflect a prevalence estimate.
- Despite these limitations, data from CPDR recapitulates previous epidemiological findings of increased Parkinson's disease risk both with increasing age and among men.
- 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 (May 31, 2020).