California Parkinson’s Disease Registry
Program Summary April 2022

CPDR Data Flow

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

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

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

4. 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

- Total Records: 534,583
- Deduplicated Cases: 93,928

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.

<table>
<thead>
<tr>
<th>Entry Method</th>
<th>Records</th>
<th>Facilities</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Automated</td>
<td>453,192</td>
<td>215</td>
<td>64,571</td>
</tr>
<tr>
<td>Manual Entry</td>
<td>81,391</td>
<td>335</td>
<td>29,357</td>
</tr>
<tr>
<td>Total</td>
<td>534,583</td>
<td>550</td>
<td>93,928</td>
</tr>
</tbody>
</table>

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.

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