California Parkinson’s Disease Registry
Program Summary June 2020

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

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

4. **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

- **Total Records**: 272,243
- **Deduplicated Cases**: 71,671

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.

<table>
<thead>
<tr>
<th>Entry Method</th>
<th>Records</th>
<th>Facilities</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Automated</td>
<td>240,366</td>
<td>212</td>
<td>48,238</td>
</tr>
<tr>
<td>Manual Entry</td>
<td>31,877</td>
<td>318</td>
<td>23,433</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>272,243</strong></td>
<td><strong>530</strong></td>
<td><strong>71,671</strong></td>
</tr>
</tbody>
</table>

### 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.

*Source: California Parkinson’s Disease Registry (May 31, 2020).*
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).