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The California Parkinson's Disease Registry Pilot Project 2006 - 2010: An Assessment and
Validation of Medical Records from Patients Living in the California Central Valley

A thesis submitted in partial satisfaction
of the requirements for the degree Master of Science
in Epidemiology

by

Lauren Claire Byrne

2021

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ABSTRACT OF THESIS

The California Parkinson's Disease Registry Pilot Project 2006 - 2010: An Assessment and
Validation of Medical Records from Patients Living in the California Central Valley

by

Lauren Claire Byrne

Master of Science in Epidemiology

University of California, Los Angeles, 2021

Professor Beate R. Ritz, Chair

The California Parkinson's Disease Registry (CPDR) pilot project established in Central California to examine the feasibility of establishing a Parkinson's disease (PD) registry for the entire state of California. PD cases, along with date of diagnosis, ICD-9 codes, and demographic information, was ascertained from 70 medical facilities in Fresno, Kern, and Tulare Counties. Cases of PD denoted by an ICD-9 code of 332.0 were used to determine crude, and gender and age specific incidence rates of PD in each county from 2007-2010. An additional random sample of 358 PD patient records (121 complete records) were selected for further analysis of clinical symptoms. When validated against UK Parkinson's Disease Society Brain Bank Research Center criteria (UKBB PD) diagnostic criteria¹, according to the charts, 67.8% of all reported cases were considered to be correctly diagnosed as a parkinsonian syndrome; of these 51.2 % were considered to be definite cases of idiopathic PD.

The thesis of Lauren C. Byrne is approved.

Elizabeth R. Mayeda

Roch Nianogo

Beate R. Ritz, Committee Chair

University of California, Los Angeles

2021

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Introduction

Neurodegenerative disorders increasingly contribute to global disability.² Prominent among them, is Parkinson's disease (PD). PD is a chronic neurodegenerative disease characterized by the loss of dopaminergic neurons in the substantia nigra pars compacta of the midbrain. PD diagnosis is primarily based on a clinical diagnosis referring to the presence of characteristic motor and non-motor symptoms.³ The prevalence of Parkinson's disease (PD) seems to be accelerating faster than many other neurological disorders.⁴ Much of this increase might be attributed to increasing life expectancy, improved data collection methods, increased awareness of the disease and diagnosing, and possibly environmental exposures linked to industrial and farming processes.⁴ Reports of a rising prevalence of PD have provided the impetus to explore methods to build state PD registries that enumerate PD patients and their demographic features and eventually allow for research and planning related to medical care needs in this patient population.⁵ Registry data would also allow for the identification of heterogeneity in the spatial or trends in the temporal distribution of PD patients across race/ethnicity and socioeconomic groups, and possibly also allow conducting studies that examine contributions to disease etiology from environment exposures.⁶

In 2004, the California State Assembly passed bill No. 2248, inaugurating California Codes, Health and Safety Code, Sections 103860-103865 for PD reporting. This bill established PD as a reportable disease, required healthcare institutions which were treating patient with PD to report these patients to a PD registry, and permitted registry personnel access to patients' medical records. The California Parkinson's Disease Registry (CPDR) was therein born. California's large and diverse population makes it an ideal state for expanding the understanding of the distribution and etiology of this disease. The CPDR offers unparalleled opportunities for

comprehensive statewide data collection and the development of transparent statewide prevalence and incidence estimates for PD.

Population-based disease data relies upon accurate diagnoses to avoid misclassification errors. Valid registration of incident PD is inherently difficult as the diagnosis of PD and the differential diagnosis of parkinsonian disorders are primarily based upon the accuracy of clinical evaluations; there are currently no definitive diagnostic biomarkers or tests.^{7,8} Diagnostic accuracy is also influenced by age⁹, PD stage and disease duration (improved with duration of disease)^{10,11,7,12} physician specialization^{13,14}, and new developments in the understanding of PD etiology and pathology.¹⁵ An added difficulty is that symptoms associated with atypical parkinsonism syndromes may not be easily detectable in early disease states: progressive supranuclear palsy (PSP), multiple systems atrophy (MSA), corticobasal degeneration (CBD), Lewy body dementia(LBD), and vascular parkinsonism(VaP).¹⁶ Thus, it is important to ascertain not only the feasibility, but the validity of the data collected from different clinical sources that populate a statewide PD registry.

In this report we describe the California Parkinson's Disease Registry pilot project that intended to assess the feasibility of several active data collection methods and also the efficacy, validity, and accuracy of clinical diagnoses of PD by a diverse healthcare provider system in the predominantly rural California Central Valley.

Methods

Data Collection

To identify PD cases for this registry pilot project, in spring 2008, an active case ascertainment approach was utilized to acquire medical records of patients with PD from a select

group of health care practitioners. Time and cost restraints limited the scope of data collection to neurology practices and medical facilities known to serve patients with PD. Of 469 possible practices and providers, trained registry abstraction staff contacted 113 providers that were likely PD care providers, including hospitals and medical practices within the California Central Valley counties of Fresno, Kern, and Tulare. These 113 providers were identified from among previous collaborators of the Parkinson's, Environment, and Gene (PEG) Study and internet searches focusing on neurological practices. Registry staff informed the personnel at these facilities about the new registry legislation that established the CPDR and explained the required reporting and confidentiality procedures. Visits were also scheduled for registry staff to abstract data from medical records of patients with PD. The initial contact was attempted via post-mail and/or email and approximately 20% of the mailings/emails were returned as undeliverable due to incorrect or outdated information for offices that no longer existed, as physicians had retired or moved. In all instances, mailings were followed up with a phone call, though some facilities remained unreachable.

In compliance with HIPAA standard operating procedure, patient data was collected in-person using encrypted electronic devices or locked paper lists. Records were obtained for individuals that fulfilled the Inclusion Criteria of: 1) an International Classification of Disease code (ICD-9 code) of 332.0 (primary or idiopathic PD), 333.0 (other degenerative disease of the basal ganglia) , 332.1 (secondary parkinsonism or parkinsonism due to drugs or induced by neuroleptics), or 331.82 (dementia with Lewy bodies) and 2) a record for a healthcare visit between January 1, 2006 and December 31, 2010 within Fresno, Kern, and Tulare counties.

Medical facilities and practices were required to report information on date of PD diagnosis, diagnosing physician, patient's date of birth, full name, gender, current address, race, as well as ICD-9 codes.

The data collection (including medical chart reviews to collect PD symptom data) process varied by facility, requiring time investments that ranged from 30 minutes to entire days, depending upon the details and extent of data provided to or abstracted by the registry staff. Medical facilities and practices with electronic systems were easily able to generate a list of eligible patients and the above listed requested variables, while other practices needed to abstract all data manually from records. If the electronically generated lists contained missing variables, the patient's medical records were examined by hand. A search of the billing system based on the inclusion criteria was also found to be an efficient method for generating lists of eligible PD patients. Some hospitals had staff preparing data on behalf of their physicians while at other facilities the physicians themselves reported the data. Some physicians worked at multiple clinics/hospitals, and this may have contributed to duplicate records if the physician and the hospital reported the same patients independently to CPDR. Thus, we instituted a protocol at the CPDR to identify and removed duplicate patient reports before tabulating patient characteristics.

Clinical Abstraction

To validate the PD diagnoses of patients reported to the CPDR, a sample of up to 20 eligible patients from each medical facility or practice were randomly selected for clinical abstraction of detailed medical information. Patients' medical charts were examined for the date of first PD diagnosis, medications utilized, and clinical symptoms of PD recorded, specifically the cardinal signs of PD: resting tremor, bradykinesia, cogwheel rigidity, and postural instability.

Additional symptoms abstracted included: tremor, slowness, slow movement, rigidity, increased tone, unstable gait, falling, loss of balance, difficulty with balance, unsteadiness, and responsiveness to dopamine agonists (Levodopa carbidopa). To determine the validity of the ICD-9 codes as a reporting tool for the registry, symptoms observed by the reporting physician were compared to the UK Brain Bank Clinical Diagnostic (UKBB) Criteria. The UKBB defines a parkinsonian syndrome as: 1) having bradykinesia and at least rigidity, (resting) tremor, or postural stability, 2) not meeting exclusion criteria 3) and 3 supportive positive criteria for PD.¹ Exclusion criteria not documented within the charts were systematically documented as absent.

Assessment of Parkinson's Disease Incidence and Clinical Abstraction

PD incidence was established by the annually by the date of diagnosis reported in medical records. We operated under the assumption that the patient did not receive a PD diagnosis previously at any other facility in- or outside the tri-county area prior to 2007; i.e., a facility that did report PD, as there was no central institution collecting such data or enforcing PD registration after the law in 2004 was enacted as an 'unfunded mandate.' All medical facilities were required by law to report PD to the CPDR starting in 2006. However, since the cases reported by a facility within the service date of 2006 were a mixture of incident and prevalent cases, only cases reported after 2006 were considered to be incident cases of PD. Therefore, 2007 is the first year that incidence could be established. Age and gender adjusted incidence estimates were calculated using the annual county population estimates estimated from the 5 years estimates (2006-2010) of the US Census Bureau's 2010 American Community Survey (ACS)¹⁷, with age and gender adjustment to the 1990 U.S. Census population

distribution¹⁸. As we intended to compare the incidence in this with previous studies, the 1990 U.S. Census population was utilized as a standard instead of 2000 or 2010 reports.

Various reported symptoms abstracted from the medical charts were utilized to assess the validity of a PD diagnosis according to the four cardinal and additional symptoms. Due to potential heterogeneity in recording symptoms between practices, the wording was allowed to vary in order to capture the four cardinal symptoms of resting tremor, bradykinesia, cogwheel rigidity and postural instability. Tremor refers to the mention of a resting tremor or tremor of the face or the upper or lower extremities; bradykinesia denotes any mention of bradykinesia, slowness, or slow movement; rigidity includes rigidity, cogwheel rigidity, or increased tone. Lastly, posture and gait instability indicates any discussion of postural instability, falling, loss of balance, difficulty with balance, unstable gait, and unsteadiness in the chart. Other criteria and symptoms such as, asymmetry ever or at onset, dopamine agonist benefit, continuous levodopa treatment for 3+ years, and progressive disorder, were utilized in establishing UKBB criteria.¹

All analysis was conducted with SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Results

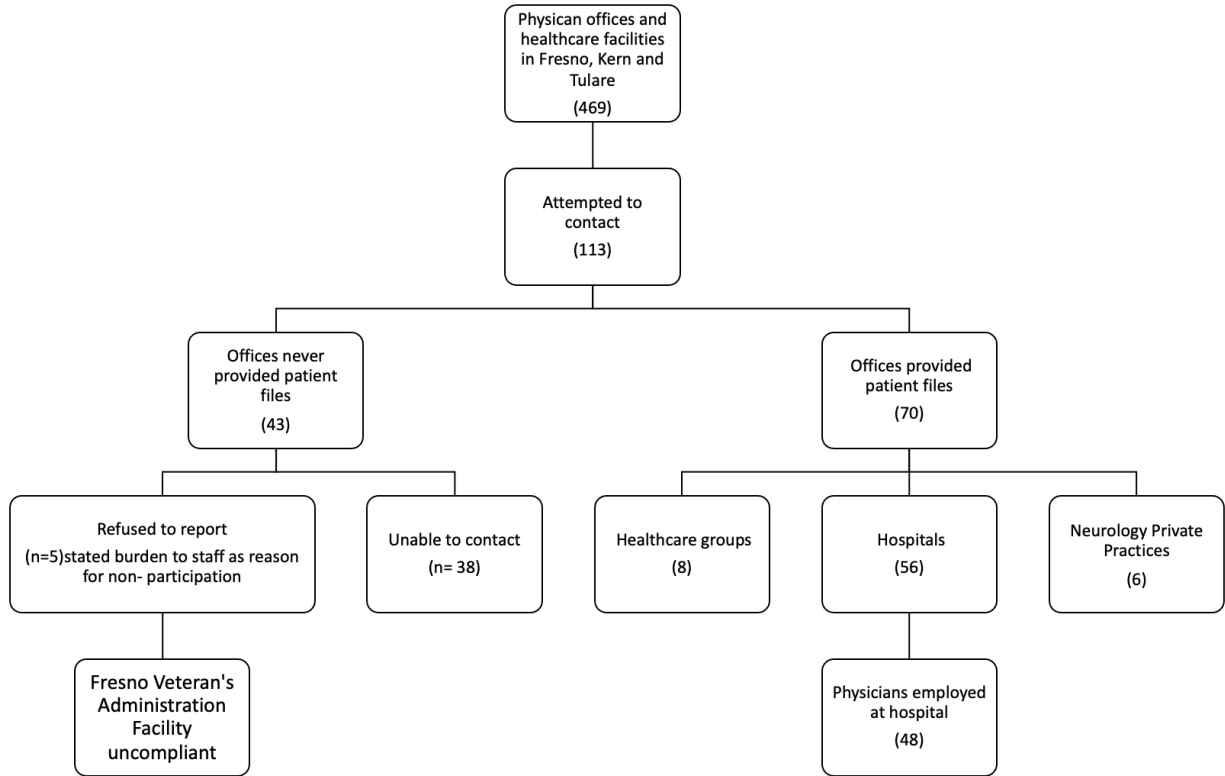
Of the 70 health care facilities, 56 were hospitals (with 48 physicians (including neurologist) employed), 8 were health care groups, and 6 were neurology private practices. (Figure 1).

Feasibility of Data Collection

Approximately 62% of the 113 (n= 70) health care facilities we reached out to agreed to provide patient medical information and allowed their own staff or CPDR staff to review

records. Of the 113 contacted offices, a total of 38% (n= 43) never replied to our request or chose not to participate because they either reported to not serve any PD patients or failed to establish contact with CPDR staff. Some practices were hesitant to participate or refused participation because of concerns and confusion regarding the release of private health information (HIPAA violation), the time and labor required to generate requested patient information from paper medical records, or uncertainty about the difficulty in selecting records for review even though CPDR staff attempted to assure them of the legal context and provided staff support. Of the 43 offices, 12% (n=5) outright refused participation or cooperation; this included the Fresno Veteran's Administration clinic, who cited that as federally funded facility, they did not have to comply with state law. Some facilities even obtained legal counsel; however, they eventually conceded because of the law's clear mandate. While a penalty for non-compliance was established, the registry staff agreed not to enforce fines in the best interest of establishing a good rapport with all facilities. Consequently, no protocol was developed for non-compliance. Despite these hurdles, we were very appreciative that majority of providers were quite willing to cooperate. The providers reported their main motivation for participation stemmed from their sense of social responsibility and appreciation of increased research opportunities offered by a PD registry.

Figure 1 – Pilot California Parkinson’s disease Registry Medical Facilities and Physician Offices from Jan 1, 2006 – Dec 31, 2010, in Fresno, Kern, and Tulare Counties



Demographics

A total of 5,385 unique PD patients were reported as having been seen by one of the responding health care providers during our pilot program’s ascertainment period between January 1, 2006, and December 31, 2010, in the tri-county area of California’s Central Valley. In total, 83.9 % (n= 4,518) of these patients had an ICD-9 code 332.0 (Parkinson’s disease). The distribution of prevalent and incident cases of PD by biological sex, age, county, race, and year of diagnosis are presented with Table 1. The majority of cases were male (54.4%; n= 2,458) and over 95% (n =4,309) of cases were 55 years old and older. (Please reference Appendix A.1 –

A.3, for demographic distributions for those 55+ years old.) There was a fairly even distribution of each county with Tulare contributing the least at 28.7% (n=1,295) compared to Fresno (36.4%; n =1,647) and Kern (34.9%, n=1,576). Given the population size of each county, this indicates an under-reporting of patients from Fresno County most likely because we were unable to collect data from the Fresno VA Hospital that is a large health care provider in the area. For a majority racial information has to be considered unknown (50.9%, n= 2,299) and another large group was reported as Non-Hispanic White (40.7%, n= 1,838). Lastly, the number of estimated presumed incident cases dropped from 2006 (33.7%, n= 1,521) to 2007 (21.8%, n= 986), suggesting that we likely considered too many prevalent cases as incident in 2006 especially as the number of newly recorded cases was stable in 2008 (22.3%, n= 1,009). The number dropped again further in 2009 (15.0%, n= 678) and 2010 (7.2%, n= 324), most likely because the efforts at reaching offices were winding down as funding for the pilot effort ran out and active reporting could not be supported anymore in the same way by our staff. Thus, the years 2007 and 2008 may be reflecting the most accurate incidence data for these counties – with the caveat that we under-recorded for Fresno. The annual age and gender adjusted PD incidence rates per 100,000 person-years for 2007-2010 respectively in Fresno, Kern, and Tulare counties (Tables 2, 3, 4).

Table 1 Demographics of CPDR Incident Cases 2006 - 2010

| | <i>n (%)</i> |
|--|--------------|
| <u>Total</u> | 4518 (100) |
| <u>Biological Sex</u> | |
| Female | 2060 (45.6) |
| Male | 2458 (54.4) |
| <u>Age Group</u> | |
| < 20 | 3 (0.1) |
| 20 - 29 | 10 (0.2) |
| 30 - 44 | 51 (1.1) |
| 45 - 54 | 145 (3.2) |
| 55 - 64 | 516 (11.4) |
| 65 - 74 | 956 (21.2) |
| 75 - 84 | 1777 (39.3) |
| > = 85 | 1060 (23.5) |
| <u>County</u> | |
| Fresno | 1647 (36.4) |
| Kern | 1576 (34.9) |
| Tulare | 1295 (28.7) |
| <u>Race</u> | |
| Asian | 49 (1.1) |
| Black/African American | 77 (1.7) |
| Hispanic | 255 (5.6) |
| Non-Hispanic White | 1838 (40.7) |
| Other/Unknown | 2299 (50.9) |
| <u>Year of Diagnosis</u> | |
| 2006 | 1521 (33.7) |
| 2007 | 986 (21.8) |
| 2008 | 1009 (22.3) |
| 2009 | 678 (15.0) |
| 2010 | 324 (7.2) |
| ** Only living, primary cases of incident PD with 332.00ICD-9 codes and located in Fresno, Kern or Tulare County included. | |

Table 2- Estimated Parkinson's disease Incidence in Fresno County, CA from 2007-2010

| | <u>Census Pop</u> | <u>Census weights</u> | 2007 | | | | 2008 | | | | 2009 | | | | 2010 | | | |
|-------------------|-------------------|-----------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|
| | | | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> |
| Total | 1.73E+08 | 1.73E+08 | 357 | 602077 | 59.29 | 29.90 | 376 | 601720 | 62.49 | 31.35 | 229 | 601344 | 38.08 | 20.11 | 50 | 601115 | 8.32 | 4.21 |
| Sex by Age | | | | | | | | | | | | | | | | | | |
| <i>Female</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 19618240 | 0.113 | 0 | 69444 | 0.00 | 0.00 | 0 | 69444 | 0.00 | 0.00 | 0 | 69444 | 0.00 | 0.00 | 0 | 69444 | 0.00 | 0.00 |
| 30 - 44 | 30006772 | 0.174 | 2 | 86193 | 2.32 | 0.40 | 2 | 86191 | 2.32 | 0.40 | 0 | 86189 | 0.00 | 0.00 | 0 | 86189 | 0.00 | 0.00 |
| 45 - 54 | 12996990 | 0.075 | 6 | 56694 | 10.58 | 0.80 | 4 | 56688 | 7.06 | 0.53 | 0 | 56684 | 0.00 | 0.00 | 0 | 56684 | 0.00 | 0.00 |
| 55 - 64 | 11100981 | 0.064 | 17 | 42073 | 40.41 | 2.59 | 21 | 42056 | 49.93 | 3.21 | 7 | 42035 | 16.65 | 1.07 | 0 | 42028 | 0.00 | 0.00 |
| 65 - 74 | 10062013 | 0.058 | 35 | 24755 | 141.39 | 8.23 | 35 | 24720 | 141.59 | 8.24 | 26 | 24685 | 105.33 | 6.13 | 6 | 24659 | 24.33 | 1.42 |
| 75 - 84 | 5823804 | 0.034 | 69 | 16717 | 412.75 | 13.90 | 71 | 16648 | 426.48 | 14.37 | 49 | 16577 | 295.59 | 9.96 | 8 | 16528 | 48.40 | 1.63 |
| > = 85 | 1590216 | 0.009 | 37 | 9092 | 406.95 | 3.74 | 49 | 9055 | 541.14 | 4.98 | 17 | 9006 | 188.76 | 1.74 | 4 | 8989 | 44.50 | 0.41 |
| Total | 91199016 | 0.528 | 166 | 304968 | 54.43 | 29.67 | 182 | 304802 | 59.71 | 31.72 | 99 | 304620 | 32.50 | 18.89 | 18 | 304521 | 5.91 | 3.46 |
| <i>Male</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 18837237 | 0.109 | 0 | 74024 | 0.00 | 0.00 | 0 | 74024 | 0.00 | 0.00 | 1 | 74024 | 1.35 | 0.15 | 0 | 74023 | 0.00 | 0.00 |
| 30 - 44 | 28618633 | 0.166 | 3 | 88435 | 3.39 | 0.56 | 2 | 88432 | 2.26 | 0.37 | 2 | 88430 | 2.26 | 0.37 | 0 | 88428 | 0.00 | 0.00 |
| 45 - 54 | 12267987 | 0.071 | 9 | 56055 | 16.06 | 1.14 | 5 | 56046 | 8.92 | 0.63 | 9 | 56041 | 16.06 | 1.14 | 4 | 56032 | 7.14 | 0.51 |
| 55 - 64 | 9867255 | 0.057 | 21 | 40270 | 52.15 | 2.98 | 22 | 40249 | 54.66 | 3.12 | 20 | 40227 | 49.72 | 2.84 | 7 | 40207 | 17.41 | 0.99 |
| 65 - 74 | 7871539 | 0.046 | 49 | 21557 | 227.30 | 10.35 | 48 | 21508 | 223.17 | 10.16 | 37 | 21460 | 172.41 | 7.85 | 7 | 21423 | 32.68 | 1.49 |
| 75 - 84 | 3518561 | 0.020 | 70 | 12165 | 575.42 | 11.71 | 79 | 12095 | 653.16 | 13.29 | 46 | 12016 | 382.82 | 7.79 | 10 | 11970 | 83.54 | 1.70 |
| > = 85 | 697378 | 0.004 | 39 | 4603 | 847.27 | 3.42 | 38 | 4564 | 832.60 | 3.36 | 15 | 4526 | 331.42 | 1.34 | 4 | 4511 | 88.67 | 0.36 |
| Total | 81678590 | 0.472 | 191 | 297109 | 64.29 | 30.16 | 194 | 296918 | 65.34 | 30.94 | 130 | 296724 | 43.81 | 21.48 | 32 | 296594 | 10.79 | 5.05 |

*All Fresno County age and gender person years are estimated from the 5 years estimates (2006-2010) of the US Census Bureau's 2010 American Community Survey (ACS)

**Standardized to the 1990 U.S. Census population age and gender distribution

Table 3- Estimated Parkinson's disease Incidence in Kern County, CA from 2007-2010

| | <u>Census Pop</u> | <u>Census weights</u> | 2007 | | | | 2008 | | | | 2009 | | | | 2010 | | | |
|-------------------|-------------------|-----------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|
| | | | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> |
| Total | 172877606 | 172877606 | 360 | 538898 | 66.80 | 37.33 | 420 | 538538 | 77.99 | 44.46 | 204 | 538118 | 37.91 | 21.74 | 101 | 537914 | 18.78 | 10.99 |
| Sex by Age | | | | | | | | | | | | | | | | | | |
| <i>Female</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 19618240 | 0.113 | 0 | 56285 | 0.00 | 0.00 | 0 | 56285 | 0.00 | 0.00 | 0 | 56285 | 0.00 | 0.00 | 0 | 56285 | 0.00 | 0.00 |
| 30 - 44 | 30006772 | 0.174 | 3 | 77093 | 3.89 | 0.68 | 3 | 77090 | 3.89 | 0.68 | 1 | 77087 | 1.30 | 0.23 | 0 | 77086 | 0.00 | 0.00 |
| 45 - 54 | 12996990 | 0.075 | 2 | 50813 | 3.94 | 0.30 | 8 | 50811 | 15.74 | 1.18 | 4 | 50803 | 7.87 | 0.59 | 0 | 50799 | 0.00 | 0.00 |
| 55 - 64 | 11100981 | 0.064 | 17 | 36071 | 47.13 | 3.03 | 23 | 36054 | 63.79 | 4.10 | 13 | 36031 | 36.08 | 2.32 | 7 | 36018 | 19.43 | 1.25 |
| 65 - 74 | 10062013 | 0.058 | 29 | 21510 | 134.82 | 7.85 | 43 | 21481 | 200.18 | 11.65 | 22 | 21438 | 102.62 | 5.97 | 12 | 21416 | 56.03 | 3.26 |
| 75 - 84 | 5823804 | 0.034 | 72 | 13183 | 546.16 | 18.40 | 81 | 13111 | 617.80 | 20.81 | 36 | 13030 | 276.29 | 9.31 | 22 | 12994 | 169.31 | 5.70 |
| > = 85 | 1590216 | 0.009 | 41 | 5000 | 820.00 | 7.54 | 36 | 4959 | 725.95 | 6.68 | 25 | 4923 | 507.82 | 4.67 | 11 | 4898 | 224.58 | 2.07 |
| Total | 91199016 | 0.528 | 164 | 259955 | 63.09 | 37.79 | 194 | 259791 | 74.68 | 45.10 | 101 | 259597 | 38.91 | 23.09 | 52 | 259496 | 20.04 | 12.28 |
| <i>Male</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 18837237 | 0.109 | 1 | 68528 | 1.46 | 0.16 | 0 | 68527 | 0.00 | 0.00 | 1 | 68527 | 1.46 | 0.16 | 1 | 68526 | 1.46 | 0.16 |
| 30 - 44 | 28618633 | 0.166 | 7 | 88088 | 7.95 | 1.32 | 3 | 88081 | 3.41 | 0.56 | 0 | 88078 | 0.00 | 0.00 | 1 | 88078 | 1.14 | 0.19 |
| 45 - 54 | 12267987 | 0.071 | 5 | 54580 | 9.16 | 0.65 | 13 | 54575 | 23.82 | 1.69 | 3 | 54562 | 5.50 | 0.39 | 1 | 54559 | 1.83 | 0.13 |
| 55 - 64 | 9867255 | 0.057 | 27 | 35473 | 76.11 | 4.34 | 34 | 35446 | 95.92 | 5.47 | 13 | 35412 | 36.71 | 2.10 | 6 | 35399 | 16.95 | 0.97 |
| 65 - 74 | 7871539 | 0.046 | 41 | 19763 | 207.46 | 9.45 | 66 | 19722 | 334.65 | 15.24 | 24 | 19656 | 122.10 | 5.56 | 11 | 19632 | 56.03 | 2.55 |
| 75 - 84 | 3518561 | 0.020 | 66 | 9730 | 678.31 | 13.81 | 72 | 9664 | 745.03 | 15.16 | 44 | 9592 | 458.72 | 9.34 | 19 | 9548 | 198.99 | 4.05 |
| > = 85 | 697378 | 0.004 | 49 | 2781 | 1761.96 | 7.11 | 38 | 2732 | 1390.92 | 5.61 | 18 | 2694 | 668.15 | 2.70 | 10 | 2676 | 373.69 | 1.51 |
| Total | 81678590 | 0.472 | 196 | 278943 | 70.27 | 36.83 | 226 | 278747 | 81.08 | 43.74 | 103 | 278521 | 36.98 | 20.24 | 49 | 278418 | 17.60 | 9.55 |

*All Kern County age and gender person years are estimated from the 5 years estimates (2006-2010) of the US Census Bureau's 2010 American Community Survey (ACS)

**Standardized to the 1990 U.S. Census population age and gender distribution

Table 4- Estimated Parkinson's disease Incidence in Tulare County, CA from 2007-2010

| | | Tulare County | | | | | | | | | | | | | | | | |
|-------------------|-------------------|-----------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|--------------|---------------------|--------------------------------|-------------------------|
| | | 2007 | | | | 2008 | | | | 2009 | | | | 2010 | | | | |
| | <u>Census Pop</u> | <u>Census weights</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> | <u>Count</u> | <u>Person Yrs.*</u> | <u>Incidence (per 100,000)</u> | <u>Std. Incidence**</u> |
| Total | 1.73E+08 | 1.73E+08 | 269 | 273934 | 98.20 | 48.01 | 212 | 273665 | 77.47 | 39.37 | 245 | 273453 | 89.59 | 47.76 | 173 | 273208 | 63.32 | 32.82 |
| Sex by Age | | | | | | | | | | | | | | | | | | |
| <i>Female</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 19618240 | 0.113 | 0 | 30562 | 0.00 | 0.00 | 0 | 30562 | 0.00 | 0.00 | 0 | 30562 | 0.00 | 0.00 | 0 | 30562 | 0.00 | 0.00 |
| 30 - 44 | 30006772 | 0.174 | 1 | 40934 | 2.44 | 0.42 | 0 | 40933 | 0.00 | 0.00 | 0 | 40933 | 0.00 | 0.00 | 0 | 40933 | 0.00 | 0.00 |
| 45 - 54 | 12996990 | 0.075 | 2 | 25636 | 7.80 | 0.59 | 3 | 25634 | 11.70 | 0.88 | 4 | 25631 | 15.61 | 1.17 | 1 | 25627 | 3.90 | 0.29 |
| 55 - 64 | 11100981 | 0.064 | 9 | 19172 | 46.94 | 3.01 | 6 | 19163 | 31.31 | 2.01 | 18 | 19157 | 93.96 | 6.03 | 20 | 19139 | 104.50 | 6.71 |
| 65 - 74 | 10062013 | 0.058 | 19 | 11455 | 165.87 | 9.65 | 17 | 11436 | 148.65 | 8.65 | 33 | 11419 | 288.99 | 16.82 | 14 | 11386 | 122.96 | 7.16 |
| 75 - 84 | 5823804 | 0.034 | 43 | 7405 | 580.69 | 19.56 | 36 | 7362 | 489.00 | 16.47 | 48 | 7326 | 655.20 | 22.07 | 28 | 7278 | 384.72 | 12.96 |
| > = 85 | 1590216 | 0.009 | 41 | 3337 | 1228.65 | 11.30 | 28 | 3296 | 849.51 | 7.81 | 21 | 3268 | 642.59 | 5.91 | 7 | 3247 | 215.58 | 1.98 |
| Total | 91199016 | 0.528 | 115 | 138501 | 83.03 | 44.54 | 90 | 138386 | 65.04 | 35.83 | 124 | 138296 | 89.66 | 52.01 | 70 | 138172 | 50.66 | 29.10 |
| <i>Male</i> | | | | | | | | | | | | | | | | | | |
| 20 - 29 | 18837237 | 0.109 | 0 | 32601 | 0.00 | 0.00 | 1 | 32601 | 3.07 | 0.33 | 0 | 32600 | 0.00 | 0.00 | 1 | 32600 | 3.07 | 0.33 |
| 30 - 44 | 28618633 | 0.166 | 2 | 41843 | 4.78 | 0.79 | 2 | 41841 | 4.78 | 0.79 | 1 | 41839 | 2.39 | 0.40 | 0 | 41838 | 0.00 | 0.00 |
| 45 - 54 | 12267987 | 0.071 | 6 | 25293 | 23.72 | 1.68 | 2 | 25287 | 7.91 | 0.56 | 12 | 25285 | 47.46 | 3.37 | 3 | 25273 | 11.87 | 0.84 |
| 55 - 64 | 9867255 | 0.057 | 22 | 18212 | 120.80 | 6.89 | 7 | 18190 | 38.48 | 2.20 | 17 | 18183 | 93.49 | 5.34 | 16 | 18166 | 88.08 | 5.03 |
| 65 - 74 | 7871539 | 0.046 | 32 | 10168 | 314.71 | 14.33 | 25 | 10136 | 246.65 | 11.23 | 23 | 10111 | 227.48 | 10.36 | 25 | 10088 | 247.82 | 11.28 |
| 75 - 84 | 3518561 | 0.020 | 52 | 5538 | 938.97 | 19.11 | 61 | 5486 | 1111.92 | 22.63 | 54 | 5425 | 995.39 | 20.26 | 42 | 5371 | 781.98 | 15.92 |
| > = 85 | 697378 | 0.004 | 40 | 1778 | 2249.72 | 9.08 | 24 | 1738 | 1380.90 | 5.57 | 14 | 1714 | 816.80 | 3.29 | 15 | 1700 | 882.35 | 3.56 |
| Total | 81678590 | 0.472 | 154 | 135433 | 113.71 | 51.89 | 122 | 135279 | 90.18 | 43.31 | 121 | 135157 | 89.53 | 43.01 | 103 | 135036 | 76.28 | 36.96 |

*All Tulare County age and gender person years are estimated from the 5 years estimates (2006-2010) of the US Census Bureau's 2010 American Community Survey (ACS)
 **Standardized to the 1990 U.S. Census population age and gender distribution

Clinical Data Abstraction

A simple random sample of 358 (8%) of the 4,518 individuals identified to have PD were selected for their medical records to be abstracted for clinical features of PD. Complete data was available for 121 records; of which the distribution of cardinal symptoms of presumed incident cases of PD in 2006 to 2010 by biological sex, age, county, and race are presented with Table 3. Similar to results in Table 1, the majority of cases were male (58%; n= 69) and 55 years old or older (96.6%, n= 115) or had a racial identity that is considered as other or unknown (60.5%, n= 72) or as Non-Hispanic White (37%, n= 44). The majority of cases resided in Kern County (60.5%, n= 72), while very few were from Fresno County (9.2%, n= 11). Using our comprehensive definition of the four cardinal symptoms of PD out of the 119 medical charts, 85.7% (n=102) indicated tremor, 68.1% (n=81) bradykinesia, 73.1% (n= 87) cogwheel rigidity and as many as 62.2% (n= 74) noted posture and gait instability (Table 5).

Table 5 - Demographic Characteristics of Cardinal Symptoms Noted as Present

| | <i>n (%)</i> | <i>Tremor</i> | <i>Bradykinesia</i> | <i>Rigidity</i> | <i>Posture & Gait</i> |
|-----------------------|--------------|---------------|---------------------|-----------------|---------------------------|
| Total n (%) | 119 (100) | 102 (85.7) | 81 (68.1) | 87 (73.1) | 74 (62.2) |
| Biological Sex | | | | | |
| Female | 50 (42) | 44 (37) | 32 (26.9) | 30 (25.2) | 32 (26.9) |
| Male | 69 (58) | 58 (48) | 49 (41.2) | 57 (47.9) | 42 (35.3) |
| Race | | | | | |
| Asian | 3 (2.5) | 2 (1.7) | 1 (0.8) | 3 (2.52) | 3 (2.5) |
| White | 44 (37) | 39 (32.8) | 33 (27.7) | 34 (28.6) | 31 (26.1) |
| Other/Unknown | 72 (60.5) | 61 (51.3) | 47 (39.5) | 50 (42) | 40 (33.6) |
| Age | | | | | |
| 44 - 54 | 4 (3.4) | 4 (3.4) | 4 (3.4) | 4 (3.4) | 3 (2.5) |
| 55 - 64 | 11 (9.2) | 11 (9.2) | 8 (6.7) | 11 (9.2) | 4 (3.4) |
| 65 - 74 | 24 (20.2) | 22 (18.5) | 20 (16.8) | 17 (14.3) | 16 (13.5) |
| 75 - 84 | 50 (42.0) | 44 (37.0) | 38 (31.9) | 38 (31.9) | 30 (25.21) |
| >= 85 | 30 (25.2) | 21 (17.7) | 11 (9.2) | 17 (14.3) | 21 (17.7) |
| County | | | | | |
| Fresno | 11 (9.2) | 8 (6.7) | 8 (6.7) | 10 (8.4) | 6 (5) |
| Kern | 72 (60.5) | 65 (54.6) | 52 (43.7) | 56 (47.1) | 46 (38.7) |
| Tulare | 36 (30.3) | 29 (24.4) | 21 (17.7) | 21 (17.7) | 22 (18.5) |

Only living, primary cases of PD with 332.0 ICD-9 codes and located in Fresno, Kern or Tulare County included.

Tremor = resting tremor or tremor of the face or the upper or lower extremities

Bradykinesia = bradykinesia, slowness, or slow movement

Rigidity = cogwheel rigidity, rigidity or increased tone

Posture and gait instability = postural instability, falling, loss of balance, difficulty with balance, unstable gait, and unsteadiness

Symptoms were not considered present if noted absent or questionable, could not be defined, or were not documented in chart

Missing: n = 2

When using the exact wording only for the 4 cardinal symptoms (resting tremor, bradykinesia, cogwheel rigidity and postural instability) (Appendix C), a total of 81.2% (n=99) of the charts mentioned between 1 and 4 of these; specifically, 5.8% (n=7) mentioned all four symptoms, 24% (n=29) recorded three, 27% (n=33) mentioned two, and 24.8% (n=30) only one of these symptoms; leaving 18.1% (n = 22) reporting none. As seen in Table 6, 14 patients' medical charts used one of the less specific terms instead such that 95% (n=113) of the charts mentioned between 1 and 4 of the cardinal symptoms of PD and 26.7% (n=44) reported all 4, leaving only 5% (n =6) reporting none.

Table 6 - Demographic Characteristics of Comprehensive Cardinal Symptoms of Parkinson's disease (PD) from Chart Abstraction

| Number of Cardinal Symptoms | n | Reported by Different Practices | Sex | | Age | | | | Race | | | County | | |
|------------------------------|------------|---------------------------------|-----------|-----------|-----------|-----------|-----------|-----------|---------|-----------|-----------|----------|-----------|-----------|
| | | | Female | Male | 44 - 64 | 65 to 74 | 75 to 84 | 85+ | Asian | White | Other | Fresno | Kern | Tulare |
| 0 | 6 (5.0) | 5 (50) | 2 (1.7) | 4 (3.4) | 0 (0.0) | 1 (0.8) | 2 (1.7) | 3 (2.5) | 0 (0.0) | 2 (1.7) | 4 (3.4) | 1 (0.8) | 3 (2.5) | 2 (1.7) |
| 1 | 10 (8.4) | 5 (50) | 4 (3.4) | 6 (5.04) | 0 (0.0) | 1 (0.8) | 5 (4.2) | 4 (3.4) | 0 (0.0) | 2 (1.7) | 8 (6.7) | 0 (0.0) | 5 (4.2) | 5 (4.2) |
| 2 | 19 (16.0) | 8 (80) | 12 (10.1) | 7 (5.9) | 3 (2.5) | 2 (1.7) | 5 (4.2) | 9 (7.6) | 1 (0.8) | 3 (2.5) | 15 (12.6) | 2 (1.7) | 9 (7.6) | 8 (6.7) |
| 3 | 40 (33.6) | 10 (100) | 18 (15.1) | 22 (18.5) | 5 (4.2) | 10 (8.4) | 17 (14.3) | 8 (6.7) | 1 (0.8) | 16 (13.5) | 23 (19.3) | 4 (3.4) | 24 (20.2) | 12 (10.1) |
| 4 | 44 (26.7) | 9 (90) | 14 (11.8) | 30 (25.2) | 7 (5.88) | 10 (8.4) | 21 (17.7) | 6 (5.0) | 1 (0.8) | 20 (16.8) | 23 (19.3) | 4 (3.4) | 31 (26.1) | 9 (7.6) |
| Total with at least 1 | 113 (95.0) | 10 (100) | 48 (40.4) | 65 (54.6) | 15 (12.6) | 23 (19.3) | 48 (40.4) | 27 (22.7) | 3 (2.5) | 41 (34.5) | 69 (58.0) | 10 (8.4) | 69 (58.0) | 34 (28.6) |
| Total | 119 (100)* | 10 (100) | 50 (42.0) | 69 (58.0) | 15 (12.6) | 24 (20.2) | 50 (42.0) | 30 (25.2) | 3 (2.5) | 43 (36.1) | 73 (61.3) | 11 (9.2) | 72 (60.5) | 36 (30.3) |

Tremor = resting tremor or tremor of the face or the upper or lower extremities
 Bradykinesia = bradykinesia, slowness, or slow movement
 Rigidity = cogwheel rigidity, rigidity or increased tone
 Posture and gait instability = postural instability, falling, loss of balance, difficulty with balance, unstable gait, and unsteadiness
 * 2 of 121 missing

When the medical charts identified by ICD-9 as PD were assessed according to the UK Brain Bank Parkinson's disease diagnostic criteria, 82 (67.8%) were classified as parkinsonism meaning the individual exhibited bradykinesia and at least one of the following: rigidity, (resting) tremor, or postural/gait stability and were examined to have not have exclusion criteria. Of the 82, 42 were classified as definite clinical PD; in addition to the above requirements, these individuals had at least 3 supportive positive criteria for PD. (Table 5)

| Table 7 - Abstracted medical records with Parkinson's disease ICD-9 codes validated by UK Brain Bank Parkinson's disease diagnostic criteria | | | | | | | | | | | |
|--|----------------------|---------------|-----------------|--|---------------------------|-----------------------|-----------------------|---------------------------------|---|-----------------------------|-----------------------------------|
| | UKBB Step 1 Criteria | | | | UKBB Step 3 Criteria | | | | | | |
| | <i>Bradykinesia</i> | <i>Tremor</i> | <i>Rigidity</i> | <i>Postural & Gait Instability</i> | <i>Asymmetry at Onset</i> | <i>Asymmetry Ever</i> | <i>Resting Tremor</i> | <i>Dopamine Agonist Benefit</i> | <i>Continuous Levodopa Treatment for 3+ years</i> | <i>Progressive Disorder</i> | <i>PD Diagnosis 10 years+ ***</i> |
| UKBB Definite Diagnosis of Parkinson's Disease (n = 42) | | | | | | | | | | | |
| Noted Present | 42 (100.0) | 42 (100.0) | 38 (90.5) | 26 (58.02) | 21 (50.0) | 5 (11.9) | 34 (81.0) | 31 (73.8) | 7 (16.7) | 39 (92.9) | 11 (26.8) |
| Noted Absent, Not Available or Questionable | 0 (0.0) | 0 (0.0) | 4 (9.5) | 16 (61.9) | 21 (50.0) | 37 (88.1) | 8 (19.0) | 11 (26.2) | 35 (83.3)* | 3 (7.1)** | 30 (73.2) |
| UKBB Diagnosis of Parkinsonian Syndrome (n = 82; includes n =42 Definite Cases) | | | | | | | | | | | |
| Noted Present | 82 (100.0) | 78 (95.1) | 70 (85.4) | 54 (65.9) | 22 (26.8) | 6 (7.3) | 50 (61.0) | 41 (50.0) | 10 (12.2) | 54 (65.9) | 11 (14.5) |
| Noted Absent, Not Available or Questionable | 0 (0.0) | 4 (4.9) | 12 (14.6) | 28 (34.2) | 60 (73.2) | 75 (92.7) | 32 (39.0) | 41 (50.0) | 72 (87.8)* | 28 (34.1)** | 65 (85.5) |
| Tremor = resting tremor or tremor of the face or the upper or lower extremities Bradykinesia = bradykinesia, slowness, or slow movement Rigidity = cogwheel rigidity, rigidity or increased tone Posture and gait instability = postural instability, falling, loss of balance, difficulty with balance, unstable gait, and unsteadiness *Continuous Levodopa Treatment was defined as: absent, not available, questionable, or no benefit and stopped **Progressive Disorder defined as: absent, not available, questionable, or cannot be defined *** Missing: n = 1 of 42 and n = 6 of 82 | | | | | | | | | | | |

Discussion

This PD registry pilot study assessed the feasibility of data collection and the possibility to validate the diagnosis with medical chart abstraction. We contacted 113 medical facilities in Fresno, Kern, and Tulare Counties and 70 responded and allowed the review of medical records for patients with ICD-9 codes identifying at PD. Of these records, 121 records with complete medical data were abstracted for medical records and compared against the UKBB PD diagnostic criteria.

Feasibility of Data Collection

Financial constraints and lack of a uniform, county-wide medical record system or EHRs did not allow us to review all PD patients' medical charts, thus we randomly selected up to 20 charts from 22 facilities; the 121 complete records came from 10 of these facilities. With

increased employment of electronic health records (EHRs), the workload required may be reduced and cooperation in registry efforts thus increase.

Demographics

As expected, PD incidence increased with age except for the very old (85+) and that males (54.4%) contributed a higher number of cases compared to females (45.6%) consistent with our previous research report in which we assembled PD cases in the same tri-county population between 2000 and 2006 ¹⁹, except that we would have expected more males. This can most likely be attributed to an undercount of males with PD due to the lack of reporting by the Veteran Affairs Hospital in Fresno County. Consequentially, the PD incidence in Fresno County were also lower and likely underestimated due to this under enumeration of male Veterans. CPDR data collection in and after 2008 was more limited, most likely resulting in an underestimation of PD incidence.

Of the reported race the majority of PD white non-Hispanic (36.08%; n =1665) and Hispanic (5.31%; n= 245). The races of 56.94% (n=2628) of cases were considered either other or mostly unknown. This is expected as many medical practices do not record their patients' race. Identifying racial trends in disease is important for establishing targeted interventions/outreach and for enhancing our understanding of genetic trends. In further development of the CPDR, it important to make race a required field entry within medical records and registry forms.

Clinical Data Abstraction

The distribution of males (58%) within the abstracted medical charts reflected the distribution of males within the overall CPDR cases (45.7% female, 54.4% male). Over 96% of patients for whom medical charts were abstracted were 65 years of age or older which reflects the PD age distribution in CPDR (95.4%). While almost 51% of the CPDR cases were considered other or unknown races, over 60% of the abstracted cases were other or unknown. Very few Asians (n=3) and no Black/African American or Hispanics were included within the abstracted cases. While those who identify with these races are very likely within the “unknown race” category, the generalizability of these abstracted cases to these counties is questionable given that these counties have large Hispanic populations. Together with overall racial profile from the CPDR, this lack of data on racial and ethnic background highlights the importance of requiring race and ethnicity reporting on medical records and future CPDR registry forms imbedded within EHRs.

Within the analysis, more comprehensive definitions were utilized for the 4 cardinal symptoms of PD: tremor (both resting and not), bradykinesia (including slowness), rigidity (cogwheel, muscle rigidity, or increased tone) and postural and gait instability. Utilizing multiple different symptoms to define our 4 cardinal symptoms enhanced the number of patients considered to have that symptomology. Only 47.1% (n= 57) of charts reported the singular symptom of resting tremor; however, when adopting additional criteria to define symptoms increased the number of medical records noting any tremor to 85.7% (n=102) of the records. Similarly, of the original records, bradykinesia symptoms increased from 55.4% (n=67) to 68.1% (n=81), rigidity symptoms increased from cogwheel rigidity 54.6% (n=66) to 73.1% (n=87) and postural and gait symptoms increased from 17.4 % (n=21) to 62.2% (n= 74) reporting. This

supports the notion of developing holistic criteria within modern day EHR registry algorithms. Such criteria can improve the likelihood of identifying true cases of PD and is mindful of the various terminology utilized by different physicians based on specialty, medical education, practice and/or hospital affiliation.

According to the UK Parkinson's Disease Society Brain Bank Research Center criteria, 82 of the 121 (PPV = 67.8%) charts identified by ICD-9 codes were considered to be accurately diagnosed as a parkinsonian syndrome; of these 82, 51.2 % (n = 42; 34.7% of 121) were considered to be a definite diagnosis of PD. This is on the lower end of what may be expected from comparable validation studies. A 2016 systematic review and meta-analysis spanning a 25-year period calculated a pooled diagnostic accuracy of 82.7% (95% CI: 62.6- 93.0%) utilized the UKBB criteria.²⁰

The thoroughness and transcription of the exam varied across the 10 practices and medical facilities from which the complete medical charts were abstracted. The number of practices reporting 1 to 4 of the cardinal symptoms, ranged from 5 to 10 practices and medical facilities; their specialty is unknown. While a moderately high frequency, the number of charts contributed by each practice and facility was somewhat inconsistent with a few practices reporting far more cases with 3 or 4 cardinal symptoms than others. (Appendix E). However, since the identities of the medical practices and facilities were not known to assure the practitioners of confidentiality, it is not clear whether practice type, such as hospital, group practice, or private practice, impacted these trends. Another explanation could be the neurologists' level of expertise and the number of patients with PD the neurologist typically sees. Further investigation should consider to which physicians simply make diagnoses and which physicians note clinical features of PD as present or absent within their patients' medical charts.

Discovering trends among family practice physicians, neurologists, or movement disorder specialists can advance the development of targeted interventions that improve exams by all physicians and the transcription of their medical records. This in turn will allow for more accurate reporting of PD cases and the clinical features to the CPDR.

Regardless, inconsistencies within reported symptomology across medical practices and facilities in the tri-county area reveals a need for standardization of charting methods for those treating persons with PD. Now that medical practices have shifted from paper records to EHRs, it is more feasible to implement standardized interfaces within EHR systems giving all physicians the options to be uniform in their reporting and treating of persons with PD.

The findings from the CPDR pilot project provide insight that there is a great need to provide physicians and medical practice staff with resources within the EHR system to enhance the feasibility of reporting important features of PD. Ultimately, this will increase the quantity and quality of data available for a PD registry; the best information will yield the most valuable tools to benefit our health practitioners, researchers, and patients alike.

APPENDIX A.1

| <i>Appendix A.1 - Demographics of CPDR Incident Cases in those Ages 55+ in 2006 - 2010, (n = 4,518)</i> | | | |
|--|--------------|------------------------|------------------------|
| | <i>n (%)</i> | <i><=54 Yrs Old</i> | <i>>=55 Yrs Old</i> |
| <i>Total</i> | 4518 (100) | 209 (4.6) | 4309 (95.4) |
| <i>Biological Sex</i> | | | |
| Female | 2060 (45.6) | 68 (1.5) | 1992 (44.1) |
| Male | 2458 (54.4) | 141 (3.1) | 2317 (51.3) |
| <i>Race</i> | | | |
| Asian | 49 (1.1) | 2 (< 0.1) | 47 (1.0) |
| Black/African American | 77 (1.7) | 2 (< 0.1) | 75 (1.7) |
| Hispanic | 255 (5.6) | 23 (0.5) | 232 (5.1) |
| Non-Hispanic White | 1838 (40.7) | 84 (1.9) | 1754 (38.8) |
| Other/Unknown | 2299 (50.9) | 98 (2.2) | 2201 (48.7) |
| <i>County</i> | | | |
| Fresno | 1647 (36.4) | 83 (1.8) | 1564 (34.6) |
| Kern | 1576 (34.9) | 73 (1.6) | 1503 (33.3) |
| Tulare | 1295 (28.7) | 53 (1.2) | 1242 (27.5) |
| <i>Year of Diagnosis</i> | | | |
| 2006 | 1521 (33.7) | 60 (1.3) | 1461 (32.3) |
| 2007 | 986 (21.8) | 49 (1.1) | 937 (20.7) |
| 2008 | 1009 (22.3) | 49 (1.1) | 960 (21.3) |
| 2009 | 678 (15.0) | 38 (0.8) | 640 (14.7) |
| 2010 | 324 (7.2) | 13 (0.3) | 311 (6.9) |
| ** Only living, primary cases of incident PD with 332.00ICD-9 codes and located in Fresno, Kern or Tulare County included. | | | |

APPENDIX A.2

| <i>Appendix A.2 - Demographics of CPDR Incident Cases in those Ages 55+ in 2006 - 2010</i> | | | | | | |
|--|--------------|--------------------|---------------------|---------------------|---------------------|--------------------|
| | <i>n (%)</i> | <i><=54 Yrs</i> | <i>55 to 64 Yrs</i> | <i>65 to 74 Yrs</i> | <i>75 to 84 Yrs</i> | <i>>=85 Yrs</i> |
| <i>Total</i> | 4518 (100) | 209 (4.6) | 516 (11.4) | 956 (21.2) | 1777 (39.3) | 1060 (23.5) |
| <i>Biological Sex</i> | | | | | | |
| Female | 2060 (45.6) | 68 (1.5) | 216 (4.8) | 395 (8.7) | 856 (19.0) | 525 (11.6) |
| Male | 2458 (54.4) | 141 (3.1) | 300 (6.7) | 561 (12.4) | 921 (20.4) | 535 (11.8) |
| <i>Race</i> | | | | | | |
| Asian | 49 (1.1) | 2 (<0.1) | 9 (0.2) | 13 (0.3) | 11 (0.2) | 14 (0.3) |
| Black/African American | 77 (1.7) | 2 (<0.1) | 14 (0.3) | 16 (0.4) | 28 (0.6) | 17 (0.4) |
| Hispanic | 255 (5.6) | 23 (0.5) | 41 (0.9) | 51 (1.1) | 88 (2.0) | 52 (1.2) |
| Non-Hispanic White | 1838 (40.7) | 84 (1.9) | 164 (3.6) | 374 (8.3) | 755 (16.7) | 461 (10.2) |
| Other/Unknown | 2299 (50.9) | 98 (2.8) | 288 (6.4) | 502 (11.1) | 895 (19.8) | 516 (11.4) |
| <i>County</i> | | | | | | |
| Fresno | 1647 (36.4) | 83 (1.8) | 179 (3.4) | 378 (8.4) | 649 (14.4) | 358 (7.9) |
| Kern | 1576 (34.9) | 73 (1.6) | 189 (4.2) | 331 (7.3) | 602 (13.3) | 381 (8.4) |
| Tulare | 1295 (28.7) | 53 (1.2) | 148 (3.3) | 247 (5.5) | 526 (11.6) | 321 (7.1) |
| <i>Year of Diagnosis</i> | | | | | | |
| 2006 | 1521 (33.7) | 60 (1.3) | 146 (3.2) | 277 (6.1) | 599 (13.3) | 439 (9.7) |
| 2007 | 986 (21.8) | 49 (1.1) | 113 (2.5) | 205 (4.5) | 372 (8.2) | 247 (5.5) |
| 2008 | 1009 (22.3) | 49 (1.1) | 113 (2.5) | 234 (5.2) | 400 (8.9) | 213 (4.7) |
| 2009 | 678 (15.0) | 38 (0.8) | 88 (2.0) | 165 (3.7) | 277 (6.1) | 110 (2.4) |
| 2010 | 324 (7.2) | 13 (0.3) | 56 (1.2) | 75 (1.7) | 129 (2.9) | 51 (1.1) |
| ** Only living, primary cases of incident PD with 332.00ICD-9 codes and located in Fresno, Kern or Tulare County included. | | | | | | |

APPENDIX A.3

Appendix A.3 - Demographics of CPDR Incident Cases in those Ages 55+ in Fresno, Kern, and Tulare Counties, 2006 - 2010 (n = 4,518)

| | n (%) | Fresno County | | | | | | Kern County | | | | | | Tulare County | | | | | | |
|--------------------------|-------------|---------------|---------------|---------------|---------------|-----------|-------------|-------------|---------------|---------------|---------------|-----------|-------------|---------------|---------------|---------------|---------------|-----------|-------------|--|
| | | <=54 Yrs. | 55 to 64 Yrs. | 65 to 74 Yrs. | 75 to 84 Yrs. | >=85 Yrs. | Total | <=54 Yrs. | 55 to 64 Yrs. | 65 to 74 Yrs. | 75 to 84 Yrs. | >=85 Yrs. | Total | <=54 Yrs. | 55 to 64 Yrs. | 65 to 74 Yrs. | 75 to 84 Yrs. | >=85 Yrs. | Total | |
| Total | 4518 (100) | 83 (1.8) | 179 (4.0) | 378 (8.4) | 649 (14.4) | 358 (7.9) | 1647 (36.5) | 73 (1.6) | 189 (4.2) | 331 (7.3) | 602 (13.3) | 381 (8.4) | 1576 (34.9) | 53 (1.2) | 148 (3.3) | 247 (5.5) | 526 (11.6) | 321 (7.1) | 1295 (28.7) | |
| Biological Sex | | | | | | | | | | | | | | | | | | | | |
| Female | 2060 (45.6) | 28 (0.6) | 70 (1.6) | 150 (3.3) | 318 (7.0) | 196 (4.3) | 762 (16.9) | 26 (0.6) | 84 (1.9) | 136 (3.0) | 305 (6.8) | 170 (3.8) | 721 (16.0) | 14 (0.3) | 62 (1.4) | 109 (2.4) | 233 (5.2) | 159 (3.5) | 577 (12.8) | |
| Male | 2458 (54.4) | 55 (1.2) | 109 (2.4) | 228 (5.1) | 331 (7.3) | 162 (3.6) | 885 (19.6) | 47 (1.0) | 105 (2.3) | 195 (4.3) | 297 (6.6) | 211 (4.7) | 855 (18.9) | 39 (0.9) | 86 (1.9) | 138 (3.1) | 293 (6.5) | 162 (3.6) | 718 (15.9) | |
| Race | | | | | | | | | | | | | | | | | | | | |
| Asian | 49 (1.1) | 2 (<0.1) | 7 (0.2) | 7 (0.2) | 8 (0.2) | 10 (0.2) | 34 (0.8) | 0 (0.0) | 0 (0.0) | 3 (0.1) | 0 (0.0) | 1 (<0.1) | 4 (0.1) | 0 (0.0) | 2 (<0.1) | 3 (0.1) | 3 (0.1) | 3 (0.1) | 11 (0.2) | |
| Black/African American | 77 (1.7) | 1 (<0.1) | 5 (0.1) | 13 (0.3) | 15 (0.3) | 10 (0.2) | 44 (1.0) | 1 (<0.1) | 1 (<0.1) | 1 (<0.1) | 7 (0.2) | 4 (0.1) | 14 (0.3) | 0 (0.0) | 8 (0.2) | 2 (<0.1) | 6 (0.1) | 3 (0.1) | 19 (0.4) | |
| Hispanic | 255 (5.6) | 16 (0.4) | 23 (0.5) | 31 (0.7) | 45 (1.0) | 31 (0.7) | 146 (3.2) | 5 (0.1) | 7 (0.2) | 7 (0.2) | 13 (0.3) | 9 (0.2) | 41 (0.9) | 2 (<0.1) | 11 (0.2) | 13 (0.3) | 30 (0.7) | 12 (0.3) | 68 (1.5) | |
| Non-Hispanic White | 1838 (40.7) | 32 (0.7) | 60 (1.3) | 164 (3.6) | 294 (6.5) | 150 (3.3) | 700 (15.5) | 19 (0.4) | 52 (1.2) | 72 (1.6) | 135 (3.0) | 84 (1.9) | 362 (8.0) | 33 (0.7) | 52 (1.2) | 138 (3.1) | 326 (7.2) | 227 (5.0) | 776 (17.2) | |
| Other/Unknown | 2299 (50.9) | 32 (0.7) | 84 (1.9) | 163 (3.6) | 287 (6.4) | 157 (3.5) | 723 (16.0) | 48 (1.1) | 129 (2.9) | 248 (5.5) | 447 (9.9) | 283 (6.3) | 1155 (25.6) | 18 (0.4) | 75 (1.7) | 91 (2.0) | 161 (3.6) | 76 (1.7) | 421 (9.3) | |
| Year of Diagnosis | | | | | | | | | | | | | | | | | | | | |
| 2006 | 1521 (33.7) | 33 (0.7) | 64 (1.4) | 135 (3.0) | 247 (5.5) | 155 (3.4) | 634 (14.0) | 16 (0.4) | 49 (1.1) | 83 (1.8) | 190 (4.2) | 153 (3.4) | 491 (10.9) | 11 (0.2) | 33 (0.7) | 59 (1.3) | 162 (3.6) | 131 (2.9) | 396 (8.8) | |
| 2007 | 986 (21.8) | 20 (0.4) | 38 (0.8) | 84 (1.9) | 139 (3.1) | 76 (1.7) | 357 (7.9) | 18 (0.4) | 44 (1.0) | 70 (1.6) | 138 (3.1) | 90 (2.0) | 360 (8.0) | 11 (0.2) | 31 (0.7) | 51 (1.1) | 95 (2.1) | 81 (1.8) | 269 (6.0) | |
| 2008 | 1009 (22.3) | 14 (0.3) | 43 (1.0) | 83 (1.8) | 150 (3.3) | 87 (1.9) | 377 (8.3) | 27 (0.6) | 57 (1.3) | 109 (2.4) | 153 (3.4) | 74 (1.6) | 420 (9.3) | 8 (0.2) | 13 (0.3) | 42 (0.9) | 97 (2.2) | 52 (1.2) | 212 (4.7) | |
| 2009 | 678 (15.0) | 12 (0.3) | 27 (0.6) | 63 (1.4) | 95 (2.1) | 32 (0.7) | 229 (5.1) | 9 (0.2) | 26 (0.6) | 46 (1.0) | 80 (1.8) | 43 (1.0) | 204 (4.5) | 17 (0.4) | 35 (0.8) | 56 (1.2) | 102 (2.3) | 35 (0.8) | 245 (5.4) | |
| 2010 | 324 (7.2) | 4 (0.1) | 7 (0.2) | 13 (0.3) | 18 (0.4) | 8 (0.2) | 50 (1.1) | 3 (0.1) | 13 (0.3) | 23 (0.5) | 41 (0.9) | 21 (0.5) | 101 (2.2) | 6 (0.1) | 36 (0.8) | 39 (0.9) | 70 (1.6) | 22 (0.5) | 173 (3.8) | |

** Only living, primary cases of incident PD with 332.00 ICD-9 codes and located in Fresno, Kern or Tulare County included.

APPENDIX B

| Total Present, n (%) | | Resting Tremor | Tremor | Bradykinesia | Slowness | Slow Movement | Mask Face | Hypomimia | Coverted Rigidity | Rigidity | Increased Tone | Postural Instability | Falling | Loss of Balance | Difficulty with Balance | Unstable Gait | Unsteady | Dynamic Against Benefit | |
|-------------------------|-----------|----------------|-----------|--------------|-----------|---------------|-----------|-----------|-------------------|-----------|----------------|----------------------|-----------|-----------------|-------------------------|---------------|-----------|-------------------------|--|
| Biological Sex | | | | | | | | | | | | | | | | | | | |
| Female | | | | | | | | | | | | | | | | | | | |
| Noted Present | 24 (19.8) | 39 (32.2) | 26 (21.5) | 15 (12.4) | 11 (9.1) | 28 (23.1) | 3 (2.5) | 24 (19.8) | 5 (4.1) | 13 (10.7) | 8 (6.6) | 27 (22.3) | 11 (9.2) | 14 (11.6) | 3 (2.5) | 7 (5.8) | 16 (13.2) | | |
| Noted Absent | 4 (3.3) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 3 (2.5) | 0 (0.0) | 2 (1.7) | 3 (2.5) | 1 (0.8) | 4 (3.3) | 1 (0.8) | 1 (0.8) | 37 (30.6) | 1 (0.8) | 2 (1.7) | 1 (0.8) | | |
| Not Available | 24 (19.8) | 12 (9.2) | 24 (19.8) | 37 (30.6) | 41 (33.9) | 21 (17.4) | 46 (38.0) | 26 (21.5) | 44 (36.4) | 38 (31.4) | 40 (33.1) | 24 (19.8) | 40 (33.3) | 40 (33.3) | 1 (0.8) | 49 (40.5) | 43 (35.5) | 35 (28.9) | |
| Male | | | | | | | | | | | | | | | | | | | |
| Noted Present | 33 (27.3) | 51 (42.2) | 41 (33.9) | 14 (11.6) | 19 (15.7) | 36 (29.8) | 8 (6.6) | 42 (34.7) | 17 (14.1) | 22 (18.2) | 13 (10.7) | 27 (22.3) | 9 (7.5) | 15 (12.4) | 7 (5.8) | 20 (16.5) | 31 (25.6) | | |
| Noted Absent | 4 (3.3) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 5 (4.1) | 0 (0.0) | 3 (2.5) | 3 (2.5) | 0 (0.0) | 8 (6.6) | 8 (6.6) | 8 (6.6) | 2 (1.7) | 0 (0.0) | 2 (1.7) | 2 (1.7) | | |
| Not Available | 32 (26.5) | 18 (14.9) | 27 (22.3) | 54 (44.6) | 50 (41.3) | 31 (25.6) | 61 (50.4) | 24 (19.8) | 52 (43.0) | 47 (38.8) | 48 (39.7) | 34 (28.1) | 57 (47.5) | 54 (44.6) | 62 (51.2) | 47 (38.8) | 36 (29.8) | | |
| Race * 1 missing | | | | | | | | | | | | | | | | | | | |
| Asian | | | | | | | | | | | | | | | | | | | |
| Noted Present | 1 (0.8) | 2 (1.7) | 1 (0.8) | 5 (2.5) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 3 (2.5) | 3 (2.5) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | | |
| Noted Absent | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 1 (0.8) | | |
| Not Available | 2 (1.7) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 2 (1.7) | 1 (0.8) | 3 (2.5) | 0 (0.0) | 2 (1.7) | 2 (1.7) | 2 (1.7) | 2 (1.7) | 1 (0.8) | 3 (2.5) | 3 (2.5) | 2 (1.7) | 1 (0.8) | | |
| White | | | | | | | | | | | | | | | | | | | |
| Noted Present | 22 (18.3) | 38 (31.7) | 30 (25.0) | 13 (10.8) | 13 (10.8) | 25 (20.8) | 4 (3.3) | 28 (23.3) | 8 (6.7) | 12 (10.0) | 9 (7.5) | 23 (19.2) | 9 (7.5) | 14 (11.6) | 3 (2.5) | 17 (14.2) | 15 (12.5) | | |
| Noted Absent | 4 (3.3) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | 3 (2.5) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | | |
| Not Available | 18 (15.0) | 6 (5.0) | 13 (10.8) | 30 (25.0) | 31 (25.8) | 18 (15.0) | 40 (33.3) | 16 (13.3) | 35 (29.2) | 32 (26.7) | 33 (27.5) | 18 (15.0) | 33 (27.7) | 30 (25.0) | 41 (34.2) | 31 (25.8) | 27 (22.3) | | |
| Other/Unknown | | | | | | | | | | | | | | | | | | | |
| Noted Present | 34 (28.3) | 50 (41.7) | 35 (28.9) | 16 (13.3) | 16 (13.3) | 36 (29.8) | 10 (8.3) | 34 (28.3) | 13 (10.8) | 22 (18.2) | 11 (9.2) | 28 (23.3) | 10 (8.4) | 15 (12.5) | 6 (5.0) | 10 (8.3) | 30 (25.0) | | |
| Noted Absent | 4 (3.3) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 4 (3.3) | 5 (4.2) | 5 (4.2) | 2 (1.7) | 1 (0.8) | 10 (8.3) | 6 (5.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 3 (2.5) | 1 (0.8) | | |
| Not Available | 35 (28.9) | 22 (18.3) | 36 (29.8) | 57 (47.5) | 57 (47.5) | 33 (27.5) | 63 (52.5) | 34 (28.3) | 58 (48.3) | 50 (41.7) | 52 (43.3) | 39 (32.5) | 61 (51.3) | 57 (47.5) | 67 (55.8) | 56 (46.7) | 42 (34.7) | | |
| Age | | | | | | | | | | | | | | | | | | | |
| <60 | | | | | | | | | | | | | | | | | | | |
| Noted Present | 6 (5.0) | 6 (5.0) | 6 (5.0) | 1 (0.8) | 5 (4.1) | 4 (3.3) | 1 (0.8) | 5 (4.2) | 3 (2.5) | 4 (3.3) | 4 (3.3) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 3 (2.5) | 3 (2.5) | | |
| Noted Absent | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | | |
| Not Available | 1 (0.8) | 1 (0.8) | 1 (0.8) | 6 (5.0) | 2 (1.7) | 1 (0.8) | 6 (5.0) | 2 (1.7) | 4 (3.3) | 3 (2.5) | 4 (3.3) | 4 (3.3) | 4 (3.3) | 5 (4.2) | 6 (5.0) | 7 (5.8) | 4 (3.3) | | |
| 60-69 | | | | | | | | | | | | | | | | | | | |
| Noted Present | 10 (8.3) | 14 (11.6) | 12 (9.9) | 0 (0.0) | 8 (6.6) | 15 (12.4) | 4 (3.3) | 13 (10.7) | 5 (4.1) | 5 (4.1) | 5 (4.1) | 3 (2.5) | 6 (5.0) | 4 (3.3) | 5 (4.1) | 4 (3.3) | 6 (5.0) | | |
| Noted Absent | 1 (0.8) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 3 (2.5) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (1.7) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 1 (0.8) | | |
| Not Available | 7 (5.8) | 3 (2.5) | 6 (5.0) | 18 (14.9) | 10 (8.2) | 14 (11.6) | 14 (11.6) | 5 (4.2) | 13 (10.8) | 13 (10.8) | 13 (10.7) | 13 (10.7) | 11 (9.1) | 14 (11.7) | 12 (10.0) | 13 (10.7) | 11 (9.1) | | |
| 70-79 | | | | | | | | | | | | | | | | | | | |
| Noted Present | 23 (19.0) | 30 (24.8) | 28 (23.1) | 15 (12.4) | 8 (6.6) | 24 (19.8) | 4 (3.3) | 22 (18.2) | 8 (6.7) | 10 (8.3) | 8 (6.6) | 20 (16.5) | 8 (6.7) | 11 (9.0) | 4 (3.3) | 8 (6.6) | 18 (14.9) | | |
| Noted Absent | 4 (3.3) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 2 (1.7) | 2 (1.7) | 3 (2.5) | 3 (2.5) | 3 (2.5) | 1 (0.8) | 0 (0.0) | 6 (5.0) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 2 (1.7) | 0 (0.0) | | |
| Not Available | 14 (11.6) | 11 (9.1) | 12 (9.9) | 27 (22.3) | 33 (27.3) | 15 (12.4) | 37 (30.6) | 16 (13.3) | 32 (26.5) | 31 (25.6) | 27 (22.3) | 19 (15.7) | 32 (26.7) | 30 (25.0) | 37 (30.6) | 31 (25.8) | 23 (19.0) | | |
| 80-89 | | | | | | | | | | | | | | | | | | | |
| Noted Present | 14 (11.6) | 31 (25.6) | 20 (16.5) | 13 (10.8) | 8 (6.6) | 19 (15.7) | 4 (3.3) | 20 (16.5) | 6 (5.0) | 15 (12.4) | 8 (6.6) | 20 (16.5) | 8 (6.6) | 9 (7.4) | 3 (2.5) | 8 (6.6) | 17 (14.1) | | |
| Noted Absent | 3 (2.5) | 0 (0.0) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 2 (1.7) | 1 (0.8) | 2 (1.7) | 4 (3.3) | 1 (0.8) | 0 (0.0) | 1 (0.8) | 1 (0.8) | | |
| Not Available | 25 (20.7) | 11 (9.1) | 20 (16.5) | 29 (24.0) | 34 (28.1) | 23 (19.0) | 38 (31.4) | 21 (17.4) | 34 (28.1) | 26 (21.5) | 32 (26.5) | 18 (14.9) | 34 (28.3) | 33 (27.3) | 39 (32.2) | 33 (27.3) | 23 (19.0) | | |
| >=90 | | | | | | | | | | | | | | | | | | | |
| Noted Present | 4 (3.3) | 9 (7.4) | 1 (0.8) | 2 (1.7) | 1 (0.8) | 2 (1.7) | 1 (0.8) | 6 (5.0) | 6 (5.0) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 7 (5.8) | 1 (0.8) | 0 (0.0) | 4 (3.3) | 3 (2.5) | | |
| Noted Absent | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | | |
| Not Available | 9 (7.4) | 4 (3.3) | 12 (10.0) | 11 (9.1) | 12 (10.0) | 10 (8.3) | 12 (10.0) | 6 (5.0) | 13 (10.7) | 12 (10.0) | 12 (10.0) | 12 (10.0) | 6 (5.0) | 10 (8.3) | 13 (10.7) | 9 (7.4) | 10 (8.3) | | |
| County | | | | | | | | | | | | | | | | | | | |
| Franso | | | | | | | | | | | | | | | | | | | |
| Noted Present | 5 (4.1) | 6 (5.0) | 6 (5.0) | 6 (5.0) | 1 (0.8) | 7 (5.8) | 0 (0.0) | 9 (7.4) | 4 (3.3) | 1 (0.8) | 1 (0.8) | 5 (4.1) | 5 (4.1) | 2 (1.7) | 5 (4.1) | 1 (0.8) | 6 (5.0) | | |
| Noted Absent | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 4 (3.3) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | | |
| Not Available | 6 (5.0) | 5 (4.1) | 5 (4.1) | 5 (4.1) | 10 (8.2) | 4 (3.3) | 11 (9.1) | 2 (1.7) | 7 (5.8) | 10 (8.3) | 7 (5.8) | 7 (5.8) | 4 (3.3) | 8 (6.7) | 6 (5.0) | 11 (9.1) | 10 (8.3) | | |
| Kern | | | | | | | | | | | | | | | | | | | |
| Noted Present | 38 (31.4) | 63 (52.1) | 46 (38.0) | 18 (14.9) | 18 (14.9) | 40 (33.1) | 6 (5.0) | 39 (32.2) | 11 (9.1) | 28 (23.1) | 13 (10.7) | 31 (25.6) | 11 (9.2) | 16 (13.2) | 8 (6.6) | 20 (16.5) | 26 (21.5) | | |
| Noted Absent | 2 (1.7) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 5 (4.1) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 5 (4.1) | 3 (2.5) | 2 (1.7) | 1 (0.8) | 4 (3.3) | 3 (2.5) | | |
| Not Available | 33 (27.3) | 10 (8.3) | 26 (21.5) | 54 (44.6) | 55 (45.5) | 28 (23.1) | 67 (55.4) | 33 (27.3) | 60 (49.6) | 45 (37.2) | 55 (45.5) | 39 (32.5) | 59 (49.2) | 56 (46.3) | 65 (53.7) | 49 (40.5) | 44 (36.4) | | |
| Tulare | | | | | | | | | | | | | | | | | | | |
| Noted Present | 14 (11.6) | 21 (17.4) | 15 (12.4) | 5 (4.1) | 11 (9.1) | 17 (14.05) | 8 (6.6) | 18 (14.9) | 7 (5.8) | 6 (5.0) | 6 (5.0) | 8 (6.6) | 18 (14.9) | 7 (5.8) | 8 (6.6) | 2 (1.7) | 6 (5.0) | | |
| Noted Absent | 6 (5.0) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 4 (3.3) | 4 (3.3) | 1 (0.8) | 1 (0.8) | 3 (2.5) | 4 (3.3) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | | |
| Not Available | 17 (14.1) | 15 (12.4) | 20 (16.5) | 32 (26.5) | 26 (21.5) | 20 (16.5) | 29 (24.0) | 15 (12.4) | 29 (24.0) | 15 (12.4) | 30 (24.8) | 26 (21.5) | 15 (12.4) | 30 (25.0) | 29 (24.0) | 31 (25.8) | 22 (18.2) | | |

APPENDIX C

| Appendix C - Cardinal Symptoms of Parkinson's disease (PD) from chart abstraction | | |
|--|--|------------------|
| Number of Symptoms | Cardinal Symptom | <i>n</i> |
| 0 | None | 22 (18.2) |
| 1 | Resting Tremor | 4 (3.3) |
| | Bradykinesia | 5(4.1) |
| | Cogwheel Rigidity | 20 (16.5) |
| | Postural Instability | 1 (0.8) |
| | Total | 30 (24.8) |
| 2 | Resting Tremor & Bradkinesia | 15 (12.4) |
| | Resting Tremor & Cogwheel Rigidity | 6 (5.0) |
| | Resting Tremor & Postural Instability | 0 (0.0) |
| | Bradykinesia & Cogwheel Rigidity | 9 (7.4) |
| | Bradykinesia & Postural Instability | 3 (2.5) |
| | Postural Instability & Cogwheel Rigidity | 0 (0.0) |
| | Total | 33 (0.27) |
| 3 | Resting Tremor & Bradkinesia & Cogwheel Rigidity | 19 (15.7) |
| | Resting Tremor & Cogwheel Rigidity & Postural Instability | 1 (0.8) |
| | Resting Tremor& Postural Instability & Bradkinesia | 5(4.1) |
| | Bradykinesia & Cogwheel Rigidity &Postural Instability | 4 (3.3) |
| | Total | 29 (24.0) |
| 4 | Resting Tremor & Bradkinesia & Cogwheel Rigidity &Postural Instability | 7 (5.8) |
| Total with at least 1 | | 99 (81.2) |

APPENDIX D

| Appendix D - Comprehensive Cardinal Symptoms of Parkinson's disease (PD) from chart abstraction | | | | | | | | | | | | | | | |
|---|---|------------------|------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|----------------|------------------|------------------|-----------------|------------------|------------------|
| Number of Symptoms | Cardinal Symptom | n | How many Different Practices | Sex | | Age | | | | Race | | | County | | |
| | | | | Female | Male | 44 - 64 | 65 to 74 | 75 to 84 | 85+ | Asian | White | Other | Fresno | Kern | Tulare |
| 0 | None | 6 (5.0) | 5 (50) | 2 (1.7) | 4 (3.4) | 0 (0.0) | 1 (0.8) | 2 (1.7) | 3 (2.5) | 0 (0.0) | 2 (1.7) | 4 (3.4) | 1 (0.8) | 3 (2.5) | 2 (1.7) |
| 1 | Tremor | 5 (4.2) | 3 (30) | 3 (2.5) | 2 (1.7) | 0 (0.0) | 1 (0.8) | 3 (2.5) | 1 (0.8) | 0 (0.0) | 1 (0.8) | 4 (3.4) | 0 (0.0) | 3 (2.5) | 2 (1.7) |
| | Bradykinesia | 0 (0.0) | 0 (0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| | Rigidity | 2 (1.7) | 2 (20) | 0 (0.0) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 2 (1.7) | 0 (0.0) | 1 (0.8) | 1 (0.8) |
| | Postural Instability | 3 (2.5) | 2 (20) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 1 (0.8) | 2 (1.7) | 0 (0.0) | 1 (0.8) | 2 (1.7) |
| | Total | 10 (8.4) | 5 (50) | 4 (3.4) | 6 (5.04) | 0 (0.0) | 1 (0.8) | 5 (4.2) | 4 (3.4) | 0 (0.0) | 2 (1.7) | 8 (6.7) | 0 (0.0) | 5 (4.2) | 5 (4.2) |
| 2 | Tremor & Bradykinesia | 5 (4.2) | 3 (30) | 3 (2.5) | 2 (1.7) | 0 (0.0) | 1 (0.8) | 3 (2.5) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 5 (4.2) | 0 (0.0) | 2 (1.7) | 3 (2.5) |
| | Tremor & Rigidity | 4 (3.4) | 4 (40) | 1 (0.8) | 3 (2.5) | 3 (2.5) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 0 (0.0) | 1 (0.8) | 3 (2.5) | 1 (0.8) | 2 (1.7) | 1 (0.8) |
| | Tremor & Postural Instability | 6 (5.0) | 3 (30) | 5 (4.2) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 5 (4.2) | 0 (0.0) | 2 (1.7) | 4 (3.4) | 0 (0.0) | 3 (2.5) | 3 (2.5) |
| | Bradykinesia & Rigidity | 0 (0.0) | 0 (0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| | Bradykinesia & Postural Instability | 1 (0.8) | 1 (10) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 0 (0.0) | 1 (0.8) | 0 (0.0) |
| | Postural Instability & Rigidity | 3 (2.5) | 3 (30) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 2 (1.7) | 1 (0.8) | 1 (0.8) | 1 (0.8) |
| | Total | 19 (16.0) | 8 (80) | 12 (10.1) | 7 (5.9) | 3 (2.5) | 2 (1.7) | 5 (4.2) | 9 (7.6) | 1 (0.8) | 3 (2.5) | 15 (12.6) | 2 (1.7) | 9 (7.6) | 8 (6.7) |
| 3 | Tremor & Bradykinesia & Rigidity | 23 (19.3) | 9 (90) | 9 (7.6) | 14 (11.8) | 5 (4.2) | 5 (4.2) | 11 (9.2) | 2 (1.7) | 0 (0.0) | 9 (7.6) | 14 (11.8) | 3 (2.5) | 15 (12.6) | 5 (4.20) |
| | Tremor & Rigidity & Postural Instability | 9 (2.9) | 4 (40) | 4 (3.4) | 5 (4.2) | 0 (0.0) | 2 (1.7) | 3 (2.5) | 4 (3.4) | 1 (0.8) | 3 (2.5) | 5 (4.2) | 0 (0.0) | 6 (5.04) | 3 (2.5) |
| | Tremor & Postural Instability & Bradykinesia | 6 (1.9) | 3 (30) | 5 (4.2) | 1 (0.8) | 0 (0.0) | 3 (2.5) | 2 (1.7) | 1 (0.8) | 0 (0.0) | 3 (2.5) | 3 (2.5) | 0 (0.0) | 3 (2.5) | 3 (2.5) |
| | Bradykinesia & Rigidity & Postural Instability | 2 (0.6) | 3 (30) | 0 (0.0) | 2 (1.7) | 0 (0.0) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 1 (0.8) | 1 (0.8) | 1 (0.8) | 0 (0.0) | 1 (0.8) |
| | Total | 40 (33.6) | 10 (100) | 18 (15.1) | 22 (18.5) | 5 (4.2) | 10 (8.4) | 17 (14.3) | 8 (6.7) | 1 (0.8) | 16 (13.5) | 23 (19.3) | 4 (3.4) | 24 (20.2) | 12 (10.1) |
| 4 | Tremor & Bradykinesia & Rigidity & Postural Instability | 44 (37.0) | 9 (90) | 14 (11.8) | 30 (25.2) | 7 (5.88) | 10 (8.4) | 21 (17.7) | 6 (5.04) | 1 (0.8) | 20 (16.8) | 23 (19.3) | 4 (3.4) | 31 (26.1) | 9 (7.6) |
| | Total with at least 1 | 113 | 10 (100) | 48 (40.4) | 65 (54.6) | 15 (12.6) | 23 (19.3) | 48 (40.4) | 27 (22.7) | 3 (2.5) | 41 (34.5) | 69 (58.0) | 10 (8.4) | 69 (58.0) | 34 (28.6) |
| | Total | 119* | 10 (100) | 50 (42.0) | 69 (58.0) | 15 (12.6) | 24 (20.2) | 50 (42.0) | 30 (25.2) | 3 (2.5) | 43 (36.1) | 73 (61.3) | 11 (9.2) | 72 (60.5) | 36 (30.3) |

Tremor = resting tremor or tremor of the face or the upper or lower extremities
 Bradykinesia = bradykinesia, slowness, or slow movement
 Rigidity = cogwheel rigidity, rigidity or increased tone
 Posture and gait instability = postural instability, falling, loss of balance, difficulty with balance, unstable gait, and unsteadiness
 * 2 of 121 missing
 n (%) = count (frequency within 119)

APPENDIX E

| Appendix E - Practices Reporting Comprehensive Cardinal Symptoms of Parkinson's disease (PD) from Chart Abstraction | | | | | | | | | | | | |
|---|----------|-------------------------------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|
| | | | Practice | | | | | | | | | |
| Number of Symptoms | <i>n</i> | <i>How many Different Practices</i> | <i>A</i> | <i>B</i> | <i>C</i> | <i>D</i> | <i>E</i> | <i>F</i> | <i>G</i> | <i>H</i> | <i>I</i> | <i>J</i> |
| 0 | 6 | 5 (50) | 0 | 0 | 1 | 2 | 1 | 0 | 0 | 1 | 1 | 0 |
| 1 | 10 | 5 (50) | 0 | 1 | 0 | 0 | 3 | 0 | 0 | 3 | 2 | 1 |
| 2 | 19 | 8 (80) | 0 | 2 | 2 | 1 | 1 | 1 | 0 | 5 | 3 | 4 |
| 3 | 41 | 10(100) | 1 | 6 | 4 | 4 | 1 | 5 | 4 | 5 | 3 | 8 |
| 4 | 44 | 9 (90) | 0 | 8 | 2 | 5 | 1 | 10 | 5 | 2 | 4 | 7 |
| Total with at least 1 | 114* | 10 | 1 | 17 | 8 | 10 | 6 | 16 | 9 | 15 | 12 | 20 |

Cardinal Symptoms = tremor, bradkinesia, rigidity, and posture/gait instability
Each letter A- J represents one of the 10 practices
* 1 of 121 missing

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