

# Foundations for a Patient-Reported Natural History of Parkinson Disease: Cross-sectional Analysis of the MJFF Fox Insight (FI) Platform

Authors: Lakshmi Arbatti<sup>1</sup>, Andrew Nguyen<sup>2</sup>, Lauren McLaughlin<sup>3</sup>, Luba Smolensky<sup>3</sup>, Catherine Kopil<sup>3</sup>, Emily Flagg<sup>4</sup>, Carol A. Christopher<sup>1</sup>, Ira Shoulson<sup>1</sup>

<sup>1</sup>Grey Matter Technologies LLC (Sarasota, FL), <sup>2</sup>University of San Francisco, <sup>3</sup>Michael J Fox Foundation for Parkinson's Disease Research (NY, NY), <sup>4</sup>University of Rochester

## Background

The Parkinson Disease Patient Reported Outcome of Problems (PD-PROP), modeled after the Huntington Disease (HD)-PROP<sup>1</sup>, was devised to capture the verbatim accounts of PD patients about their bothersome problems (“What bothers you the most about your PD?”), the functional consequences (“In what way does this problem bother you by affecting your daily functioning?”), and problem severity (0-1-2-3 categorical scale).

Since March 2017, the PD-PROP has been embedded in the Fox Insight (FI) research platform <https://foxinsight.michaeljfox.org>, and as of November 2017, has captured keyboard-entered data on more than 5,000 consenting PD patients, including self-reported date of PD diagnosis.

## Methods

We used an analytic dataset consisting of 4998 PD patients (2648 men, 2350 women) who were within 10 years of PD diagnosis. Verbatim reports were examined by natural language processing (NLP) and n-gram analyses.

FIG 1: DISTRIBUTION BY AGE AND GENDER: TOTAL N=4998

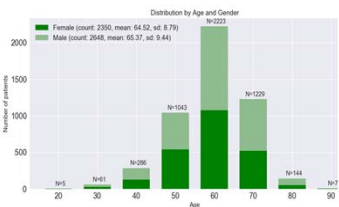
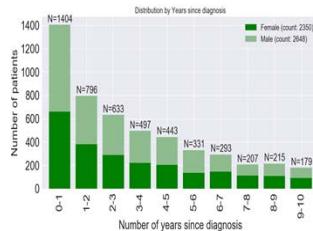


FIG 2: DISTRIBUTION OF YEARS SINCE DIAGNOSIS (N=4998 FOR RANGE 0-10 YEARS)

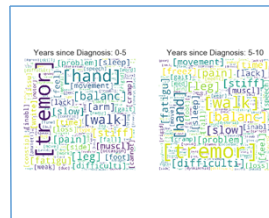


## Results

This cohort, aged 65.0 ± 9.3 years (mean ± sd) comprised a predominantly well-educated Caucasian population; 3773 patients (2018 men, 1755 women; aged 64.7 ± 9.4 years) were within 5 years of PD diagnosis (2.2 ± 1.6 years), and 1225 (630 men, 595 women; aged 66.0 ± 8.7 years) were 6-10 years of PD diagnosis (7.7 ± 1.4 years). Verbatim keyboard-captured “1st most bothersome problem” was reported by 97.7% respondents; 85.8% respondents reported up to their 5th most bothersome problem.

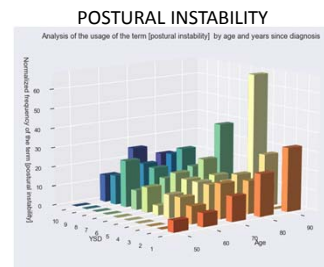
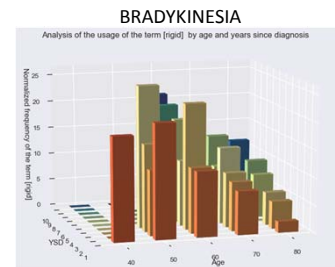
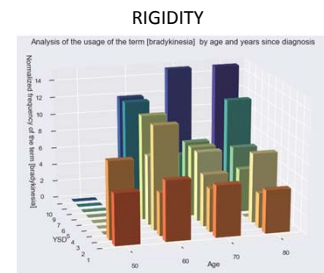
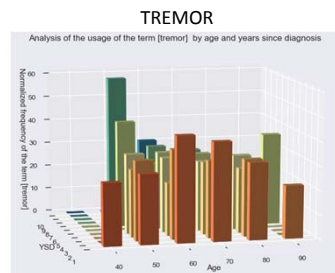
## Unigram Output of Most Bothersome Problem: 0-5 vs 5-10 yrs

FIG 3: A WORD CLOUD FOR THE UNIGRAM OF MOST BOTHERSOME PROBLEM BY YEARS SINCE DIAGNOSIS (0-5 AND 5-10 YEARS).



Among the 0-5 year PD-duration group (n=3773), Tremor>Hand>Walk>Balance>Leg were the most bothersome NLP outcomes reported compared with Tremor>Walk>Hand>Balance>Leg among the 6-10 year group (n=1225).

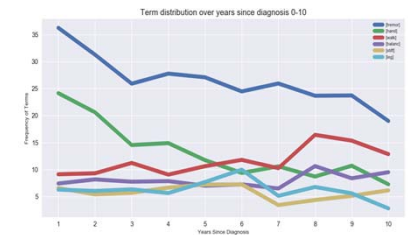
## Cardinal Clinical Motor Signs vs Patient Age and Years since Diagnosis



For each of PD cardinal motor signs (Tremor, Rigidity, Bradykinesia, Postural Instability), terms similar in meaning with frequencies of 5 or more were grouped together and normalized against the group size, then plotted against years since diagnosis and age.

## Most Bothersome Problems 0 – 10 years

FIG 5: TOP 5 UNIGRAMS WERE SELECTED FOR EACH YEAR OF DISEASE PROGRESSION FROM 0 – 10 YEARS SINCE DIAGNOSIS, AND THE NORMALIZED UNIGRAM TERM FREQUENCY WAS PLOTTED ACROSS THE TIME FRAME. THE NORMALIZED TERM FREQUENCY WAS OBTAINED BY DIVIDING THE RAW TERM FREQUENCY BY THE TOTAL NUMBER OF PATIENTS IN THAT CATEGORY.



## Conclusions

Comparing patients 0-5 vs. 6-10 years from diagnosis, Hand problems became less frequent and Walk problems more frequent with duration of PD. Overall, NLP terms referable to Tremor, Rigidity, and Bradykinesia were sustained or increased with duration of PD, while Postural Instability increased with the age of the patient as well as duration of illness.

These analyses provide a preliminary, cross-sectional, patient-reported profile of the natural history of PD that will be better informed as the Fox Insight PD-PROP cohort grows, relationship to medication is characterized, and longitudinal data are accrued. More granular analyses of other bothersome problems, their consequences and severity, as well as the application of machine learning techniques, will help better refine the utility of capturing verbatim reports of the problems that PD patients face.

## Reference

- Purks, J. L., Harris, M., Anderson, K. E. & Shoulson, I. Applying Natural Language Processing (NLP) to Verbatim Patient-Reported Outcomes. *Ann Neurology* 80, S69-S69, (2016)