

2021 FUNDING PROGRAM ANALYSIS OF PATIENT-REPORTED OUTCOMES FROM FOX INSIGHT

BACKGROUND

Parkinson's disease affects nearly 1 million people in the US and over 6 million worldwide, and those numbers are expected to rise over the coming decades. Parkinson's is highly heterogeneous: individuals experience a wide array of motor and non-motor symptoms, many of which depend on disease severity and duration. Better understanding of the lived experience of Parkinson's could drive patient-focused drug development, enhance clinical care and health outcomes, and inform public policy.

FOX INSIGHT OVERVIEW

Fox Insight is an online, longitudinal study of people with and without Parkinson's. The study collects self-reported health, patient preference, and lifestyle information; patient-reported outcomes (PROs); and genetic data with the goal of better understanding the disease. Fox Insight assessments include validated scales and novel survey instruments, which are detailed in the [Fox Insight Data Exploration Network \(Fox DEN\)](#).

With nearly 50,000 participants consented and enrollment ongoing, Fox Insight is the largest global Parkinson's cohort and a unique real-world dataset. Individuals over the age of 18 with internet access and ability to complete assessments in English are eligible to participate. The study cohort is approximately 72% people with Parkinson's with a mean age of 65 and mean Parkinson's diagnosis duration of 6.61 years. The [Fox DEN](#) platform provides investigators a tool to explore, download, and apply statistical models on data collected from volunteers in the Fox Insight study. Data are open access and investigators are encouraged to request access through Fox DEN and explore the dataset before applying to the Request for Applications (RFA).

REQUEST FOR PROPOSALS OVERVIEW

This RFA aims to understand how PROs and other volunteer contributed data in Fox Insight can contribute to better understanding of Parkinson's and inform therapeutic development, clinical care, and public policy. The Fox Insight dataset includes cross-sectional and longitudinal data from people with and without Parkinson's as well as genetic data collected by 23andMe on a subset of the Parkinson's cohort. The scale of volunteers contributing data to Fox Insight provide unprecedented power to translate patient experience into research insights, and this RFA aims to support diverse research teams to extract learnings from the community of Fox Insight participants.

While MJFF encourages investigators with diverse research expertise to apply, applicants with Parkinson's experience will be at an advantage. Study leadership and MJFF can be available to consult with applicants without Parkinson's expertise during proposal development and, if funded by MJFF, throughout the project.

DEADLINES & REVIEW SCHEDULE

- Pre-proposals Due: October 22, 2020, 5 p.m. US ET
- Full Proposal Invitations: December 21, 2020
- Full Proposals Due (by invite only): March 18, 2021, 5 p.m. US ET
- Anticipated Award Announcement: Week of May 31, 2021
- Anticipated Funding: July 2021

Applicants are encouraged to apply early to allow adequate time to correct errors found during the submission process.

FUNDING AVAILABLE

Duration: One-year grants.

Award Amount: Up to \$100,000.

Final budgets will be determined based on review of proposed work and MJFF role. These budgets include direct and indirect costs. For academic and for-profit institutions, no more than 15% or 10%, respectively, may go to indirect costs. Additional details about MJFF's indirect cost policy can be found in the [Application Guidelines](#) and [FAQ](#).

ELIGIBILITY REQUIREMENTS

Applications may be submitted by researchers or clinicians in:

- U.S. and non-U.S. biotechnology/pharmaceutical companies, or other publicly or privately held for-profit entities; and
- U.S. and non-U.S. public and private non-profit entities, such as universities, colleges, hospitals, laboratories, units of state and local governments and eligible agencies of the federal government.

PROGRAM GOAL

The Fox Insight RFA supports analysis of the PROs and genetic data collected through the Fox Insight study to elicit learnings on patient experiences that can inform therapeutic development, clinical care, public policy, and other interventions to improve patients' health outcomes.

This program is not appropriate for studies that require additional or prospective data collection.

PROGRAM PRIORITIES

Applicants should focus on analyses that achieve one or more of the following goals:

- Characterize disease progression for people with Parkinson's.
- Evaluate the utility of different instruments and/or instrument sub-items in measuring burden of disease, especially in individuals within the first two (2) years of Parkinson's diagnosis.
- Identify the role of pharmacological, medical device, and/or non-medical interventions on managing Parkinson's symptoms and long-term health outcomes.
- Predict the future health status of participants without Parkinson's based on Parkinson's risk variables and model their likelihood of developing Parkinson's.
- Determine elements of disease experience that drive patient preference and risk tolerance.
- Determine how economic factors, patient-physician communication, and lifestyle factors influence people with Parkinson's medical treatment and long-term health outcomes.
- Explore the factors that affect volunteer compliance and completeness of participation in an online study.
- Analyst-choice: Researchers can submit their own analysis topics based on available Fox Insight data especially as it relates to longitudinal analyses.

ADDITIONAL INFORMATION

Our [Application Guidelines](#) provide general guidance about applying for funding from MJFF, though the RFA always supersedes information contained in the Application Guidelines. Please note that MJFF

updated our publication and indirect costs policies in early 2020. The new [open access publication policy](#) requires articles resulting from MJFF-funded work publish in a preprint repository then in an open access forum with free and immediate readership rights.

DIVERSITY, EQUITY AND INCLUSION

In pursuit of our mission to accelerate the development of better treatments and a cure for Parkinson's disease, MJFF aims to support a rigorous research agenda reflecting a wide and diverse range of perspectives on Parkinson's disease and carried out in diverse populations. Diversity may refer to characteristics including, but not limited to, race, religion, ethnicity, sex, gender identity, sexual orientation, socioeconomic circumstance, nationality, geographic background, ability and disability, political ideology, and age. Parkinson's is a complex problem; the more angles from which we attack, the greater the chances of finding innovative scientific solutions to benefit everyone living with the disease.

As such:

- The Foundation encourages applications from diverse investigators representing groups historically underrepresented in the research enterprise.
- Because research shows that diverse teams outperform homogeneous ones, we urge applicants to share information about the composition of the team that will carry out the funded work.

INFORMATIONAL WEBINAR

MJFF will host an informational webinar on September 3, 2020, at 12 p.m. US ET to clarify and explain the goals of MJFF funding opportunities and answer applicant questions. The webinar will be available to view on-demand after the live airdate. [Register now.](#)