



**FOX
INSIGHT**

YOUR EXPERIENCE FUELING RESEARCH

**A new online Parkinson's study
from The Michael J. Fox Foundation**

AGENDA

1. What is Fox Insight?
2. What does participation in Fox Insight entail?
3. Who is eligible for Fox Insight?
4. How will data from Fox Insight be used?
5. How can you get involved?



PATIENT-POWERED RESEARCH

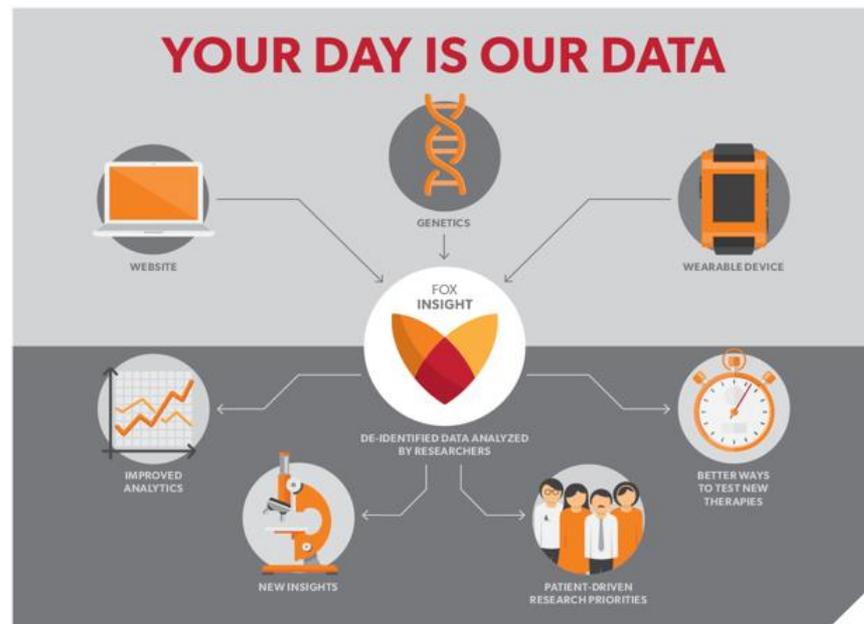
Fox Insight is an online clinical study that empowers patients, control volunteers and researchers to work together toward Parkinson's breakthroughs.

The flexible study design allows participants to contribute data in a variety of ways:

- » Routine health-related surveys
- » Optional, add-on surveys and sub-studies including genetic testing
- » Future remote data collection (e.g. wearables, keyboard tapping, biologic samples)

Broad eligibility criteria and online nature of the study removes typical barriers to entry:

- » Mobility and transportation challenges
- » Access to medical research institutions
- » Scheduling around work and family



Fox Insight participants complete virtual study visits every 3 months, and data they contribute enables high-impact scientific collaboration toward patient-relevant outcomes.



ROUTINE STUDY VISITS & OTHER RESEARCH OPPORTUNITIES

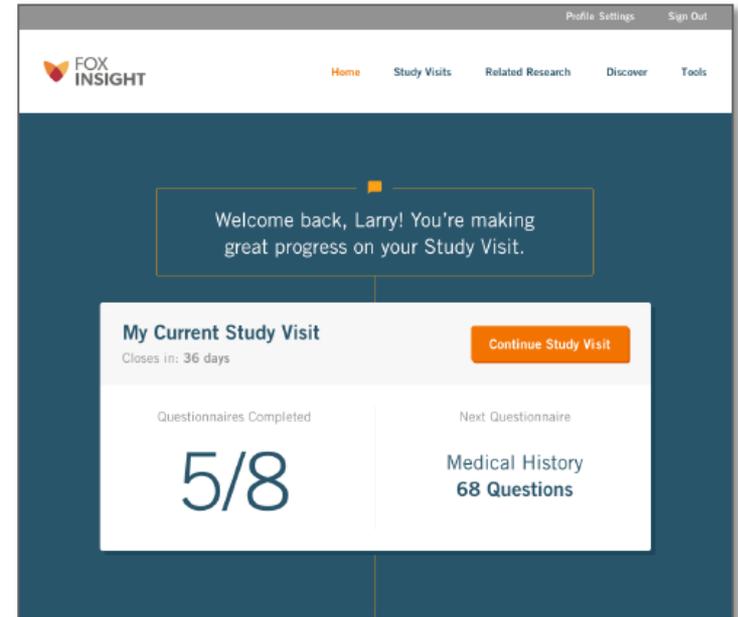
Patients contribute data every 3 months and can complete add-on activities

Through online study visits (~ 45 to 60 minutes), participants fill out a series of questionnaires to provide critical insights on:

- » Symptoms
- » Physical function
- » Medications
- » Quality of life
- » Unmet Needs
- » Healthcare preferences

Additional research opportunities such as, add-on questionnaires and sub-studies, will be integrated into the Fox Insight platform.

Data from tens of thousands of people with Parkinson's amplifies the patient voice in research, therapy approval and care delivery



THE GENETICS RESEARCH REVOLUTION

One sub-study in Fox Insight enables patients to share valuable genetic data

- » Combining genetic information with other patient insights can help researchers:
 - Correlate the genetic profile with patient perspectives,
 - Illuminate poorly understood or unknown aspects of PD and
 - Open new avenues of research toward precision medicine.
- » Participants who contribute genetic data receive 23andMe Heath + Ancestry reports and telemedicine genetic counseling for PD-associated genes at no cost.
 - PD-health report includes LRRK2 (G2019S) and GBA (N370S) status.
 - Participants can choose to share their results with genetic counselors at the Indiana University School of Medicine for counseling.



By participating in genetics research, PD patients can help **speed the development process toward personalized therapies** that may slow or stop the disease



PLATFORM RESOURCES FOR PATIENTS

Your Next Doctor Appointment



Dear Lauren,

This is a reminder from Fox Insight about your upcoming appointment with Dr. Katz at 11:15 am on Saturday, August 13th, 2016. To help you prepare, we've created the Fox Insight PD Status Report - a quick questionnaire designed by doctors to help you get the most out of your appointment. Fill it out and bring it with you - your doctor will be impressed.

Should anything related to your treatment regimen change as a result of your appointment, please take a moment to update your [Fox Insight profile](#).

[Click](#)

PHYSICIAN REPORTS

Preparing for your Next Appointment

For people with Parkinson's, a typical doctor appointment can be as short as 10-15 minutes. And getting everything you need in that short time can sometimes be a challenge.

The PD Status Report below has been designed to give your doctor a smart snapshot of what you're experiencing and what has changed since your last appointment. Fill out the report and bring it to your next appointment to make the most of your time with your doctor.

Search by date range

to [Search](#) [Create a new physician report](#)

Age: 67

First Parkinson's symptoms:
Parkinson's diagnosis: 01/2015



PHYSICIAN REPORTS

Are there new medical problems since your last visit?
I had a fall and got a few stitches in my head

Since your last visit, how is your Parkinson's disease?
Same

What aspects of your PD are worse?
Falling and tremor are worse

What aspects of your PD are better?
Not as much pain

How is your overall quality of life?
Average

How would you describe the following PD features since your last visit?

| | |
|-----------------------|---------------------------|
| Dyskinesia Worse | Stiffness Better |
| Wearing off Better | Walking Worse |
| Tremor Worse | Balance Worse |
| Slowness Better | Memory / Thinking Same |

Fox Insight volunteers have access to in-platform resources like **physician reports and appointment reminders**.



BROAD ELIGIBILITY TO PARTICIPATE

Fox Insight is currently enrolling anyone who:

- ✓ Is 18 years old or older
- ✓ Has a Parkinson's diagnosis
- ✓ Is able to complete health questionnaires in English
- ✓ Has access to the internet

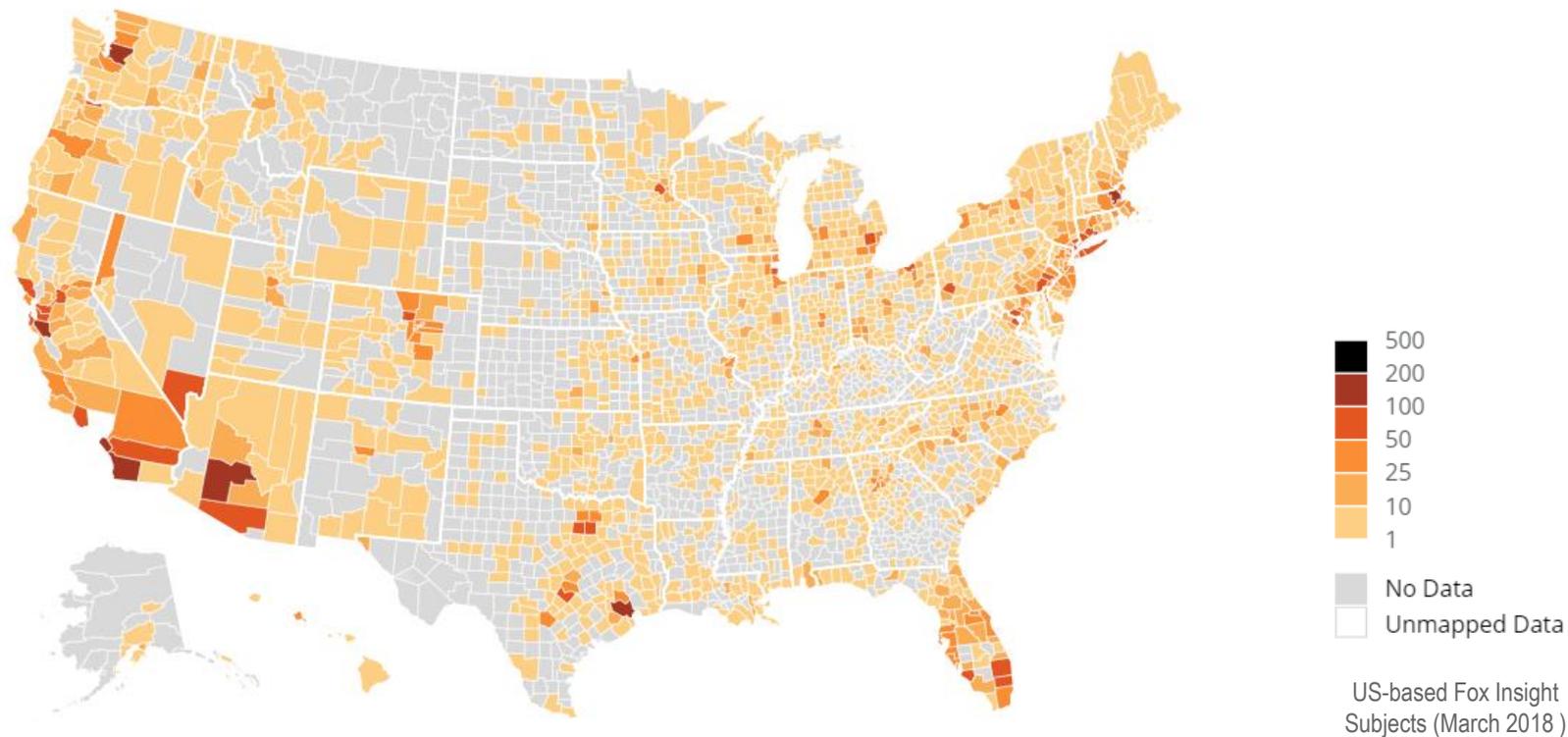
Control volunteers over the age of 18 may also participate.



Over **22,000** participants are already contributing information about their experience with PD.



BUILDING A LARGE, DIVERSE COHORT FOR RESEARCH



Data from this robust, longitudinal Parkinson's cohort **will be made available to the research community**, in near real-time, in 2019.



The Michael J. Fox Foundation for Parkinson's Research

PLAY AN ACTIVE ROLE IN ADVANCING PARKINSON'S RESEARCH

A few options to involve your Parkinson's patients

HCP Studies™ mobile app

- » Easy to use and view study information anytime, anywhere
- » Share the study instantly with patients or submit for contact by study team
- » Contact the study team with questions
- » Share the study with Parkinson's HCPs and support teams in your clinic & network

Request flyers and outreach support

- » Receive study material to display in your clinic, email/mail to your patients, and/or post on your web site
- » Contact info@foxinsight.org for questions or requests

Parkinson's patients seek to be active contributors to improved disease understanding, therapy development and care



HCP STUDIES™

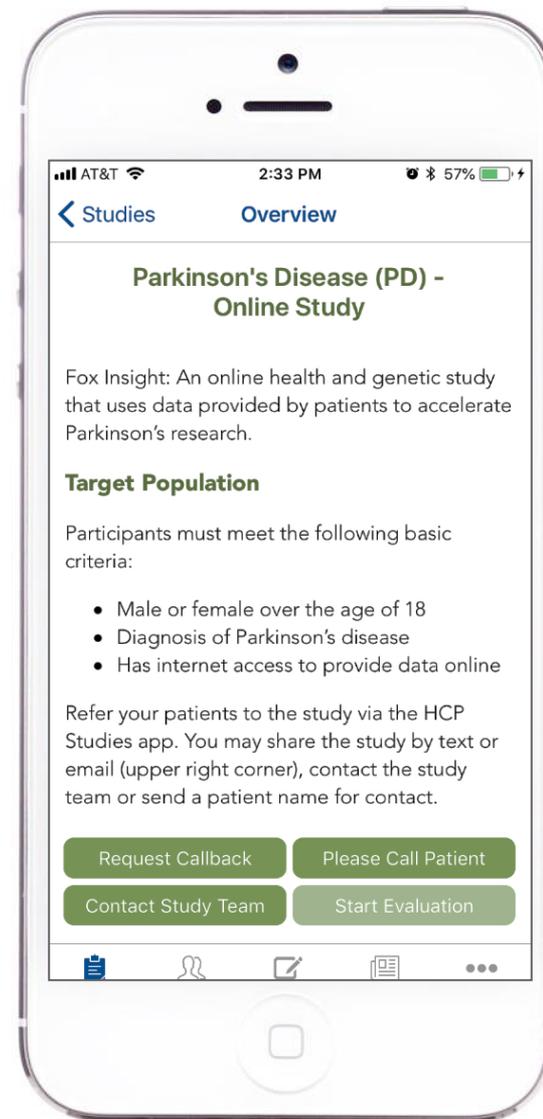
Download & Register at No Cost

Steps

- » Download (search for “HCP Studies”)
- » Register (follow simple steps)
- » Gain access to Fox Insight
- » Share Fox Insight with Parkinson’s Patients



For PC and laptop users, visit www.alturastudiesapp.com to access the web portal.



HCP Studies™ conforms to HIPAA/privacy standards



The Michael J. Fox Foundation for Parkinson's Research





THANK YOU!

Questions?

Contact: info@foxinsight.org



APPENDIX

PARKINSON'S ASSOCIATED GENES

What is LRRK2?

- » Mutations in the *LRRK2* gene are the greatest known genetic contributor to PD, accounting for 1-2% of PD cases, but more in certain ethnic groups
- » Mutations in this gene cause increased activity of the LRRK2 kinase though how this change may contribute to PD is still poorly understood

What is GBA?

- » *GBA* is another gene associated with PD; mutations in *GBA* cause lower levels of the GCase protein, a lysosomal enzyme that break down fats and other proteins in cells
- » Ongoing research aims to test the hypotheses that *GBA* mutations promote alpha-synuclein aggregation

What does it mean to have a LRRK2 or GBA mutation?

- » Not everyone with a *LRRK2* or *GBA* mutation will go on to develop PD
- » Currently, genetic status does not change the type of care PD patients receive
- » LRRK2 and GBA targeted therapies are in development, including at least 1 in clinical testing

People with PD in the U.S. can contribute genetic data to provide a more holistic picture of PD. 23andMe PD health reports include mutation status for specific LRRK2 and GBA variants.



FOX INSIGHT STUDY SYNOPSIS

STUDY POPULATION

Fox Insight Eligibility Criteria:

- » 18+ years of age
- » With or without PD
- » English-speaking
- » Internet access

Cohort Targets:

- » Enrollment: 125K
- » PD/Control ratio: 80/20
- » Demographics: Representative of PD epidemiology

PATIENT-REPORTED ASSESSMENTS

- » Medical history
- » Medications
- » Quality of Life (QoL) and activities of daily living
- » Motor and non-motor symptoms
- » Physical activity
- » Neuropsychiatric measures
- » Environmental exposure
- » Novel patient-reported outcomes (PRO) and patient preference instruments

MULTI-MODAL DATA COLLECTION

- » Genetic profiles from up to 17,000 US-based PD volunteers
- » Sensor-derived activity level data
- » Interactive voice response
- » Expanding future possibilities ...

ANCILLARY SURVEY MECHANISM

- » Opportunity for researcher-driven questionnaires (*submission process available in 2019*)
- » **Proof of concept:** 1,300 individuals with specific PD symptoms received a 15-question survey, with 300+ responses collected in < 7 days

Data from this robust, longitudinal Parkinson's cohort **will be made available to the research community**, in near real-time, in 2019.



OPEN ACCESS DATA FOR RESEARCHERS

PD Assessments

(Validated Instruments)

- PDQ-8
- EQ-5D
- MDS-UPDRS part II
- Penn Parkinson's Daily Activities Questionnaire 15 (PDAQ-15)

Additional Data Collection

- Genetic profiling (23andMe)
- Wearable sensor data
- Interactive voice response
- Investigator-driven surveys:
 - Patient reported outcome of problems
 - Patient preference for Type I/II error in clinical trials
 - ON/OFF lexicon

PD and Control Assessments

(Validated Instruments)

- Physical Activity Scale for the Elderly (PASE)
- NMS Quest
- RBD question
- GDS-15
- PD Risk Factor Questionnaire (*cross-sectional*)

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VISIT [MICHAELJFOX.ORG/FOXINSIGHT](https://www.michaeljfox.org/foxinsight)
TO LEARN MORE

