AMPLIFYING THE PATIENT VOICE IN RESEARCH

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PATIENT-POWERED RESEARCH

Fox Insight is an online clinical study that empower patients, control volunteers and researchers to work together toward Parkinson’s breakthroughs. Data from tens of thousands of participants amplifies the patient voice in R&D, therapy approval and care delivery.

» Complements traditional clinical research with scale and accessibility

» Online nature of the study allows a broader population of patients who may face geographic, mobility or transportation challenges to participate in research

» Supplements in-person studies with rigorous patient perspective data gathered over time

» Flexible design enables integration of diverse data collection modalities

Fox Insight volunteers complete virtual study visits every 90 days, and data they contribute enables high-impact scientific collaboration toward patient-relevant outcomes
PATIENT-CENTERED DESIGN

Validated PRO instruments anchor cohort characterization and support interpretation of data collected using novel patient-centered tools.

CASE STUDY 1:
- Patient Reported Outcome of Problems survey: human-centered design to capture accounts of patients’ bothersome problems
  - “What bothers you the most about your Parkinson’s disease?”
  - “In what way does this problem bother you by affecting your daily functioning?”
  - Problem severity (0-1-2-3 categorical scale)

5,000+ baseline responses

CASE STUDY 2:
- Identify meaningful benefits and risks for trial participation
  - FDA, MDIC, RTI Health Solutions, MJFF

Good research practices can elevate PPI to valid scientific evidence
  - Working with patient scientists:
    - Concept elicitation
    - Prioritization ranking survey
    - Review of attribute descriptions

4,000+ responses in 2-month recruitment window
THE FUTURE OF PERSON-CENTERED THERAPIES

Improved therapies start with patient-centered research

» Patients and care partners are the real experts on Parkinson’s

» Fox Insight has ignited a virtuous cycle of patient-centered research at MJFF
  – Patient-centric UI/UX
  – Unfiltered, direct from patient data drive:
    • Funding decisions
    • Education and public policy efforts
    • Payer relationship and industry collaboration

» Fox Insight data will be de-identified and made available to qualified investigators to speed breakthroughs

Learn more at: www.michaeljfox.org/foxinsight