PROTOCOL

Title:	Parkinson's Progression Markers Initiative (PPMI) Personal Profile
Sponsor:	Michael J. Fox Foundation for Parkinson's Research
Principal Investigator:	Thomas F Tropea, DO
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PROTOCOL APPROVAL

PPMI Personal Profile
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1. PURPOSE OF STUDY

The Parkinson Progression Marker Initiative (PPMI) is a broad program consisting of an in-clinic study (PPMI Clinical) and other complementary studies. All PPMI-affiliated studies contribute to the overarching goal to identify markers of disease progression for use in clinical trials of therapies to reduce progression of disability in Parkinson's disease (PD).

The purpose of this protocol is to establish a centralized Personal Profile that consolidates participant-reported demographic and health information across PPMI studies to support research readiness and targeted recruitment for PPMI studies and affiliated research initiatives. The Personal Profile is a non-interventional participant information component of the Parkinson Progression Marker Initiative (PPMI). Individuals may become eligible to participate in the Personal Profile after voluntarily registering in the myPPMI platform.[1]

1.1 Primary Objectives

The primary objectives of the Personal Profile are:

- to centralize participant-reported demographic, contact information and health information within a structured system to reduce repetitive data entry,
- improve data accuracy,
- maintain a single consistent source of participant information across the PPMI program, and
- support identification of individuals potentially eligible for current or future IRB approved research studies.

The Personal Profile will maintain a longitudinal record of participant updates, enhance participant engagement through a standardized onboarding pathway, and facilitate efficient identification of individuals who may be eligible for future research studies. Additionally, the system supports harmonized global survey deployment and centralized export of coded data to the Laboratory of Neuro Imaging (LONI) for secure, centralized data storage and research access in accordance with PPMI data governance policies.

2. BACKGROUND AND RATIONALE

The Parkinson Progression Marker Initiative (PPMI) is an international research program designed to identify biomarkers of disease progression to support clinical trials aimed at reducing progression of Parkinson's disease (PD) disability.

PPMI includes an in-clinic observational cohort (PPMI Clinical) and complementary studies conducted under the broader PPMI framework both online and in clinic. As the program has expanded, participant data have been collected across multiple studies and platforms, resulting in duplication of data entry efforts for participants and inefficiencies in recruitment. Participant feedback and assessment of recruitment workflows resulted in development of this initiative to improve the participant's experience and PPMI recruitment efforts, with the goal to more effectively and efficiently identify eligible participants for clinical trials based on information provided in the central profile.

The PPMI Program created the myPPMI web portal (myppmi.org) for all PPMI participants.

This website is a central dashboard for PPMI participants to have visibility to information such as their journey through the PPMI Program, status in participating studies, general news about PPMI, additional resources, or new research opportunities that may be available to them under the PPMI Program.

The Personal Profile is not an interventional study and does not test a hypothesis. It functions as a structured registry and recruitment support tool within the PPMI research ecosystem.

3. PROJECT DESIGN

This is a minimal-risk, non-interventional data collection initiative conducted via an online platform (myPPMI). This initiative involves participant-completed online questionnaires and surveys administered through the myPPMI platform. Data is collected directly from participants through self-report survey instruments.

Participants may complete structured questionnaires collecting general self-reported information, such as:

- Demographics, including contact information
- Health history
- Medication history
- Genetic history
- Current medications
- Other background information or other health related information commonly required for study eligibility screening

No experimental procedures, biospecimen collection, or clinical interventions are conducted under this protocol.

This initiative functions as a centralized recruitment support infrastructure, and a longitudinal profile update system with minimal risk to participants.

4. PARTICIPANT POPULATION

This initiative will include participants registered in the myPPMI platform. MyPPMI participation is open-ended; registration will continue as long as the platform remains active.

5. RECRUITMENT METHODS

Individuals who voluntarily register for the myPPMI platform will be invited to complete the Personal Profile. Invitations to complete the Personal Profile may occur during the onboarding process within myPPMI or through subsequent communications with existing registered participants.

Potential participants may learn about myPPMI and the Personal Profile through PPMI outreach efforts, including the PPMI website, PPMI Clinical participation, email communications, educational events, social media, advocacy partnerships, and other general recruitment campaigns. Participation in the Personal Profile is voluntary.

Registered myPPMI participants may receive periodic reminders to complete or update their

Personal Profile. Reminders may be delivered via email notifications, platform-based messages (e.g., dashboard alerts or opportunity tiles), or other standard PPMI communications. These reminders are informational in nature and do not obligate participation.

6. PARTICIPANT ELIGIBILITY

To be invited to register in myPPMI, individuals must be 18 years of age or older, and able to provide informed consent.

7. PARTICIPANT INFORMATION AND AGREEMENT TO PARTICIPATE

Participants will be provided with the electronic information sheet for the Personal Profile e prior to completing the Personal Profile questionnaires within the myPPMI platform. The information page describes the purpose of the project, what participation involves, potential risks and benefits, confidentiality protections, data sharing practices, and contact information for the study team.

Participants will be asked to review this information and acknowledge agreement to participate before proceeding to the Personal Profile.

Participation is voluntary, and participants may choose to discontinue participation at any time. Participants may also update their Personal Profile through the myPPMI platform at any time.

Because participation occurs through an online questionnaire and involves minimal risk, a waiver of documentation of consent is requested. Participants will not be asked to sign a consent form. By choosing to complete the questionnaire, they are indicating your consent to participate in this study.

8. PARTICIPANT ID ASSIGNMENT

All participants will be assigned a unique PPMI ID upon registering in myPPMI or will use their already assigned PPMI study ID. The PPMI Participant ID number will be used to identify a participant on all information collected under this protocol and associated PPMI studies.

9. PARTICIPANT ACTIVITIES

Participants will:

1. Log into the secure myPPMI portal.
2. Complete Information Sheet.
3. Complete the Personal Profile questionnaires.
4. Update profile information annually, or as needed.

Participants may skip non-required questions where permitted. No in-person visits are required.

10. RISKS TO PARTICIPANTS

The most common risk associated with online data collection is that participants may feel anxious about completing the tasks. There is a risk of disclosure of private information by participating in this initiative. However, safeguards are in place to reduce the risk of this happening. The full dataset, inclusive of identifiable data, collected for this initiative will be maintained electronically in secure databases that have undergone security reviews, and with access limited to the study team and data management partners. While every effort will be made to maintain confidentiality, there is a small risk that information may be disclosed. There may be other privacy risks that the study team may have not foreseen. No physical risks are involved. The full data Privacy Policy is available to all participants upon registration and through the portal home page.

11. POTENTIAL BENEFITS TO PARTICIPANTS

There are no direct anticipated benefits to study participants in this study. However, indirect benefits include:

1. Reduced need to repeatedly provide the same information for PPMI.
2. Potential for more efficient matching to relevant research studies.
3. Contribution to Parkinson's disease research infrastructure.

12. PARTICPANT WITHDRAWALS

Participation in the Personal Profile is voluntary. Individuals will be informed during the participant information process that they may discontinue participation at any time without penalty or loss of benefits to which they are otherwise entitled.

Participants may stop completing or updating their Personal Profile at any time. Information collected prior to withdrawal may continue to be retained and used in coded or de-identified form for research purposes.

13. PRIVACY AND CONFIDENTIALITY

Participant privacy will be protected by allowing individuals to decide whether or not to participate and by providing clear information about what data will be collected prior to participation through the participant information page.

Because participation occurs remotely through the myPPMI platform, participants may choose when and where they complete the Personal Profile questionnaires. Information collected through the Personal Profile will be stored in secure systems and accessible only to authorized members of the PPMI study team. The research team has implemented administrative, technical, and procedural safeguards designed to minimize the risk of unauthorized disclosure of identifiable information. Only authorized study personnel will have access to identifiable data required for participant management and recruitment activities. Data may be shared with qualified researchers in coded or de-identified form in accordance with PPMI data governance policies.

14. DATA SHARING AND STORAGE FOR FUTURE USE

Data collected through the Personal Profile will be stored indefinitely in secure, access-controlled databases within the PPMI infrastructure. Access to identifiable data will be limited to authorized personnel whose roles require it for purposes such as participant management, recruitment feasibility review, data quality oversight, and research analyses.

Data may be shared internally across PPMI program cores responsible for data management, participant coordination, and statistical analysis to support program operations and research activities. Data collected through the Personal Profile may also be integrated with other PPMI datasets to support harmonized analyses across the broader PPMI program.

De-identified, coded research data will be transferred to the Laboratory of Neuro Imaging (LONI), which serves as the central data repository for PPMI. Data stored at LONI may be made available to qualified researchers for approved research related to Parkinson's disease and related disorders in accordance with PPMI data access policies.

Direct identifiers will be removed before data are shared outside the PPMI study team. Any linkage files used to connect coded data to identifiable information will be maintained separately in secure systems with restricted access. All data handling will comply with applicable data protection and security standards.

15. ANALYSIS PLAN

Information collected through the Personal Profile is used solely for research infrastructure, participant database management, and identification of individuals who may be eligible for future IRB-approved studies.

Data collected will not be used to provide medical advice, establish diagnoses, or guide clinical care. This initiative is designed to support recruitment for future research opportunities. Descriptive and exploratory analyses of aggregate, de-identified data may be conducted to characterize participant demographics, health history patterns, and self-reported factors associated with Parkinson's disease risk. Findings may be used to inform research planning, study feasibility assessments, and general program development within PPMI.

16. REFERENCES

1. C. Stanley, J. Talarico, C. Fitzgerald, C. Destro, M. Mcguire Kuhl, J. Schulze, L. Heathers, E. Flagg, B. McMahon, T. Foroud, T. Tropea, K. Fabrizio, K. Marek. Creating myPPMI: an Online Portal to Deliver Study Participant Content [abstract]. *Mov Disord.* 2024; 39 (suppl 1).