

MODIFIABLE VARIABLES IN PARKINSONS

Data Use Agreement

Purpose: This ongoing natural history study, Modifiable Variables in Parkinsons (MVP), has been designed to collect patient-reported outcomes related to Parkinson's disease and evaluate whether lifestyle choices are associated with symptoms and progression. It has been a pleasure to share portions of the dataset with other researchers for use in their own projects. The purpose of this Data Use Agreement is to ensure that these data are used in a responsible manner by individuals appropriately trained in research integrity and methodology.

- I acknowledge that the quality and completeness of data cannot be guaranteed. I understand that the data are collected by self-report have not been confirmed.
- I agree to implement all safeguards appropriate to prevent the unauthorized use or disclosure of data.
- I agree to ensure that any agents, including subcontractors, to whom it provides the Data agree to the same restrictions and conditions listed in this agreement.
- I agree to provide the PI (Laurie K Mischley) with data/ information obtained from using these data.
- I agree to not use or disclose data received from Bastyr University in any manner that would constitute a violation of federal law, specifically the Health Insurance Portability and Accountability Act of 1996 and any regulations enacted pursuant to its provisions ("HIPAA Standards").
- I agree that I will not attempt to identify any Person whose information is contained in any Data or attempt to contact those Persons.
- I agree that I shall not copy, decompile, modify, reverse engineer, or create derivative works out of any of the Data.
- I agree to ensure all directors, officers, employees, contractors, and agents use or disclose the data in accordance with federal and state law.
- I agree to report in writing any unauthorized use or disclosure of the data within five (5) working days of becoming aware of an unauthorized use or disclosure.
- I agree that i will not, without the PI's prior written consent, publish or present any information or data provided or analyzed.
- I agree that I shall provide the PI with copies of any proposed publication or presentation at least two months in advance of the submission of the proposed publication or presentation to a journal, editor, or other third party. I acknowledge that the PI will have two months after receipt of the materials to object to publication or presentation if data analysis and delivery do not meet standards for scientific integrity.

- I agree that I may publish or present any material relating to the approved data request for 6 months after the date of submission of the final report submitted to the PI, or the date of termination of this agreement, as applicable.
- I agree that the PI, Laurie K Mischley ND PhD MPH, and the Database Manager and Study Coordinator, Joshua Farahnik ND(c) MPH(c), will be listed as co-authors in all publications and posters. Author order will be determined on a case-by-case basis.
- Where either party violates the terms of this agreement, the party must take immediate steps to stop the unauthorized use or disclosure and cure any resulting breach of confidentiality. Either party may terminate this agreement immediately upon written notice in the event that: (i) Bastyr University determines that the Requesting Investigator has violated a material provision of this agreement; (ii) Requesting Investigator or any of his/her employees, officers, or agents is convicted of a crime relating to, or is excluded, debarred or otherwise ineligible to participate in, any government health care program (iii) Requesting Investigator or any of his/her employees, officers, or agents is named as a defendant in a criminal proceeding for the violation of state or federal privacy and confidentiality laws.
- If any provision of this agreement, or any other agreement, document, or writing pursuant to or in connection with this agreement, is found to be wholly or partially invalid or unenforceable; the remainder of the agreement is unaffected.
- No term or provision of this agreement shall be deemed waived and no breach excused unless waiver or excuse of breach is in writing and signed by the party against whom such waiver or excuse is claimed.

Study Name: _____

Data Requestor Entity

Authorized Signature

Signature of Bastyr Designee

Printed Signature's Name

Printed Name of Bastyr Designee

Date

Date