



## **LRRK2 COHORT CONSORTIUM DATA USE AGREEMENT ("Data Use Agreement")**

I request access to data collected by The LRRK2 Cohort Consortium (LCC) for the purpose of scientific investigation and agree to the following terms of the LRRK2 Data Use Policy:

### LRRK2 Cohort Consortium Data Use Policy

Access to data collected by the LCC ("Data") will be granted according to procedures set forth by the LCC Data & Publications Committee (DPC) and in compliance with this LRRK2 Data Use Policy ("Policy"):

All access to Data must be approved in advance by the DPC. Such approval will be granted to scientific researchers, including employees or independent contractors working under the direction of such scientific researchers, and the (non-profit or for-profit) institutions at which approved scientists will conduct their research ("Recipients").

Recipients will be required to agree to the terms and conditions of this Policy prior to receiving access to Data.

Access to Data will be granted by the DPC only for scientific research purposes, which may include testing research tools, therapies or cures for commercialization. Requestors will complete a form requesting access to Data which will include, among other things, a description of the intended research use of the Data.

Recipients must agree to comply with all rules and regulations imposed by institutions at which Recipients will use the Data, including institution review board ("IRB") policies and procedures.

All Data is deidentified. Access to Data will be granted only on the condition that Recipients will not attempt to establish the identity of, or attempt to contact, subjects participating in the LCC clinical study ("Study").

1. Data may not be used:
  - a. for any purpose other than as outlined in a Recipient's proposal for access; or
  - b. in any way that conflicts with this Policy or any guidelines established by the DPC.  
During any time that Recipient is in possession of Data, Recipient must report
    - i. any important changes to the research purpose or
    - ii. changes to the principal investigator in charge of the Data included in an application for access to Data (each a "Material Change"), which Material Change will require advance approval from the DPC.
2. Data may not be shared by Recipients with anyone not affiliated with the Recipient institution (each, a "Third Party"), unless advance approval is obtained from the DPC, the proposed Third Party is participating in the research identified in the Recipient's application for access to the Data and the Third Party agrees in writing to be bound by this Policy.
3. Recipients must respond promptly and accurately to annual requests for updates on use of Data and the progress of the research for which any Data is used.

4. No Recipient or institution receiving Data may claim any intellectual property (IP) rights, including, without limitation, patent, copyright, trademark or trade secrets in Data. Neither MJFF nor the LCC may claim IP rights in any Data.
5. No Recipient or institution using Data may claim any IP rights for any invention or new work created in whole or part from Recipient's use of Data. Recipients will agree to use their best efforts to publicize to the research community any invention or new work useful to Parkinson's disease researchers created in whole or part from Data, including contacting MJFF for assistance in publicizing such invention or new work. This Section 10 shall not preclude any Recipient from claiming IP rights to any invention or work not involving in any way Recipient's use of Data ("Background IP"), even if the Data are used to test or analyze the Background IP. Any such Background IP should be identified on Recipients' proposal requesting access to Data.
6. Any IP claim in violation of Sections 4 or 5 of this Policy shall be void, and Recipient agrees to withdraw any improperly filed IP claim, whether such claim is filed in a court, to a government agency, and/or with a private party.
7. All manuscripts and abstracts/posters using data from the LCC will comply with the guidelines established and written out in the LRRK2 Cohort Consortium Publications Policy:
  - a. All manuscripts and abstracts/posters using Data shall be made freely available to the scientific research community without charge, including, at MJFF's election, through a website maintained by MJFF, unless accepted for publication by a journal of established reputation in the scientific community not controlled by Recipient whose publication policies conflict with this Section 7, in which case such publication may be in accordance with the policies of the journal.
  - b. All manuscripts and abstracts/posters using Data by Recipient will acknowledge the LCC and MJFF in the following ways:
    - i. All manuscripts using LCC data will acknowledge the methods of LCC data gathering using the following language recommended by the LCC:

“Data used in preparation of this article were obtained from the MJFF-sponsored LRRK2 Cohort Consortium (LCC). For up-to-date information on the study, visit [www.michaeljfox.org/lcc](http://www.michaeljfox.org/lcc).”
    - ii. All manuscripts and abstracts/posters will acknowledge the support of MJFF using language similar to the following:

“The LRRK2 Cohort Consortium is coordinated and funded by The Michael J. Fox Foundation for Parkinson's Research.”
    - iii. All manuscripts and abstracts/posters will acknowledge the members of the LCC (see Publication Policy for guidelines depending on publication type).



- c. All manuscripts and abstracts/posters using Data will be submitted to MJFF two weeks prior to submission to a journal so that MJFF may verify that Recipient has complied with this Section 7. MJFF may share the publication, presentation or analysis with the DPC. MJFF and the LCC will maintain confidentiality of the manuscript and will complete its review within one week of submission.
  - d. Full citation of all published manuscripts and abstracts/posters using Data will be provided to MJFF and the LCC upon acceptance to a journal or conference by emailing a copy of the manuscript or abstract/poster to [resources@michaeljfox.org](mailto:resources@michaeljfox.org).
8. Any new raw data generated from analyses of Data will be submitted to the DPC upon completion of analyses. The DPC may choose to incorporate the raw data into the LCC database.

*Important Note: It is the intent of the LCC to make Data available to investigators as quickly as possible after its receipt by the LCC. Data is locked and updated on a quarterly basis. LCC sites utilized similar, but individual, protocols; therefore, not every site collects the same data points. Furthermore, methods for obtaining data points might differ among LCC sites. The LCC worked to bring a core set of measurements together into one database for large-scale analyses.*

I am aware that the Data has limitations, including that the LCC is an ongoing project and I will take this into account in my use of Data.

Because Data may be updated (likely on a quarterly basis), in the event that I download Data for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note the version of the Data I download and I will check the database to determine if updated Data has been provided prior to submission of any material for publication.

I agree to report any use or disclosure of the Data not provided for by this Policy of which I become aware within 15 days of becoming aware of such use or disclosure.

I will ensure that any Recipients who utilize LCC Data use appropriate and administrative, physical and technical safeguards to prevent use of the Data other than as provided for by this Data Use Agreement and outlined in the application protocol.

I agree to the terms of this Policy as well as any future changes to this Policy made by the DPC, unless such changes hamper my work. If that is the case, I agree to contact the DPC to discuss such changes to understand the best way to proceed without violating terms of the Policy as amended.

I understand that failure to abide by this agreement will result in termination of my privileges to access LCC Data.

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(Signature)



**THE MICHAEL J. FOX FOUNDATION**  
**FOR PARKINSON'S RESEARCH**

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(Print Name)

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(Date of signature)