LRRK2 INVESTIGATIVE THERAPEUTICS EXCHANGE

LITE Data Use Agreement

I request access to data collected by the LRRK2 Investigative Therapeutic Exchange (LITE) initiative, supported by The Michael J. Fox Foundation for Parkinson's Research and collaborating partners, for the purpose of scientific investigation, biomarker discovery, method development, teaching, translational research, or the planning of clinical research studies and agree to the following terms:

1. I understand that I will receive coded, pseudonymized participant-level data and will under no circumstances attempt to establish the identity of, or contact, any LITE study participantI will not use LITE data, either alone or in combination with other datasets or information sources, to attempt participant re-identification.

2. I will use LITE data solely for the scientific purposes described in my approved application. I will not share, distribute, sublicense, sell, rent, lease, or otherwise transfer LITE data beyond the uses outlined in this agreement and my approved proposal.

3. I will not utilize AI tools, especially (but not exclusively) those with public-facing interfaces that do not offer guarantees regarding the containment of data inputs for LITE data, recognizing that the use of AI tools, including generative and analytical models, poses a potential risk of inadvertent data sharing due to the nature of how these tools process information and may lead to data being sent, saved, viewed, or used in unforeseen ways by parties not covered by this agreement, which is a direct violation of this agreement. See Appendix A for additional AI tool concerns, restrictions, and guidance. I will require anyone on my research team who accesses or utilizes LITE data to register through the LITE data access process and to comply with this Data Use Agreement.

4. I will comply with all applicable institutional policies, ethics committee or Institutional Review Board (IRB) requirements, and applicable laws and regulations governing the use of LITE data will provide documentation of ethical approval, exemption, or institutional authorization upon request.

5. I will implement appropriate administrative, physical, and technical safeguards to ensure secure handling and storage of LITE data. These safeguards shall include controlled access, password-protected systems, secure institutional storage, and restricted access to authorized personnel only.

6. I will report any unauthorized access, misuse, inadvertent disclosure, or suspected breach involving LITE data to the designated LITE data governance contact without undue delay and within 24 hours of becoming aware of such an event. Notifications should be sent to litedcc@indocsystems.com**.**

7. I will comply with the LITE IP policy that states:

(a) Rights to pre-existing IP or that were conceived outside of the LITE study ("Background IP") which a researcher uses in analyzing or manipulating LITE data, information, biospecimens, materials or results, remain with the investigator or institution;

(b) Intellectual property arising from discoveries made using LITE biospecimens may be pursued under institutional policies;

(c) The Michael J Fox Foundation for Parkinson's Research, as implementer of LITE, retains a non-exclusive, perpetual, sublicensable, royalty-free license for research use of IP and results discoveries arising from the use of LITE biospecimens;

(d) Access to LITE biospecimens or derived data shall not confer any ownership interest, intellectual property rights, or exclusive rights in or to LITE biospecimens, LITE data, derived datasets, or any portion thereof. In the event that the LITE biospecimens and data considered are primarily collected and made available under the Parkinson's Precision Medicine Initiative (PPMI) for which there is co-enrollment in LITE, the terms of the PPMI Biospecimen Use Agreement ,PPMI Data Use Agreement, and PPMI Publication Policy shall govern and shall prevail in the event of any conflict with this Agreement.

8. I will not use LITE data to develop systems intended to re-identify participants, infer participant identity, or generate publicly deployable models containing identifiable participant-level information.

   Development of computational or AI-based analytical methods using LITE data for scientific research purposes is permitted provided that applicable privacy safeguards are maintained, institutional governance requirements are followed, and participant confidentiality is preserved.

10. If I seek to publish manuscripts, abstracts, posters, presentations, or other scholarly outputs incorporating LITE data, I will comply with the LITE Publication Policy.

11. I agree to, upon request, submit all experimental or derived data generated from LITE data or biosamples to LITE via a LITE-designated mechanism.

Such data may include, but is not limited to:

- processed omics data,
- derived biomarker scores,
- harmonized imaging outputs,
- metadata,
- and analytical pipelines.

Derived datasets and analytical outputs will be incorporated into the LITE dataset for redistribution in accordance with LITE governance and publication policies.

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12. I understand that LITE datasets may evolve over time, analyses may be updated, and preliminary data may change as additional data become available. In publications or presentations, I will reference the dataset version and/or the date of download or access.

13.I understand that LITE's data management partners can share my user information and system activity with The Michael J. Fox Foundation for Parkinson's Research (MJFF) and LITE study leadership for purposes including governance over the use of LITE data. MJFF and LITE leadership may contact me

regarding the use of my data or for gathering feedback for improvements to the system and/or data.

14. Upon completion of the approved project, termination of access, or expiration of approval, I will handle participant-level LITE data in accordance with applicable institutional policies and LITE guidance, including secure destruction or continued secure retention where permitted.

15. I understand that failure to comply with this agreement may result in action which may include, but is not limited to, suspension or termination of access privileges, notification of my institution, and restriction from future access to LITE resources.

The Michael J. Fox Foundation and the LITE Steering Committee maintain the right to modify this policy by posting notice of such modifications on this page. Any modification becomes effective immediately upon posting the modification unless otherwise stated.

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Appendix A.

LITE DUA: Use of AI tools for Analysis of LITE Data

The **LITE Data Use Agreement ("DUA")** explicitly prohibits any individual who has obtained LITE data from sharing raw data, specifically participant-specific data, with any other individual or entity, in any forum, in any medium, except as disclosed in your data use application and only upon registration by those persons in the LITE database. This Appendix expands on paragraph 3 of the DUA, which specifically prohibits use of AI tools that do not offer guarantees regarding the containment of data.

The use of AI tools, including generative and analytical models, poses a genuine risk of inadvertent data sharing due to the nature of how AI tools process, store, and regenerate information. AI tools, including but not limited to those with public-facing interfaces, such as OpenAI's ChatGPT, usually do not offer guarantees regarding the containment of data inputs.

Any data input into a prompt or output generated from a prompt could result in the unauthorized disclosure of proprietary data. **As a result, use of LITE data with AI tools unable to guarantee that user data will not be shared is in direct violation of the DUA.**

However, an important exception to the above-stated prohibition would be AI tools, including generative and analytical models, which explicitly prevent sharing data with others. Such AI tools may be developed and internally trained by individual research groups or academic institutions for use only by the individual research group or academic institution. If such tools prevent sharing data beyond or via the tool, then LITE data may be analyzed using such AI tools.

As of the date of this Appendix, the term "Artificial Intelligence" or "AI" means a broad range of technologies and tools that can generate and regenerate content in various mediums including text, images, videos, and audio, based on input. AI tools that do not prevent sharing of inputted data pose a significant challenge in maintaining the privacy of participants in the **LITE** study, and of participants in human subjects' research in general. **Therefore, uploading LITE data to a third-party platform that is not explicitly in compliance with the prohibition on sharing LITE data is a clear violation of the DUA.**

LITE requires investigators to adhere to the following terms when deciding whether a project utilizing any AI tool complies with the DUA:

- **Computational resources**
    - The application of any statistical or other analytic methods to LITE data—whether branded as "AI" or not—must not use computational or AI resources owned by third parties who engage in the long-term retention of user content that is either shared or used in the training of public-facing models, as such activity could include the contents of the LITE data set. This includes the use of third-party platforms for inference (e.g., the inclusion of LITE data as part of an input or "prompt" for a generative language model), training (including both the training of foundation models and the fine-tuning of pre-trained models via transfer learning or some other process), prediction, or any other task that could result in LITE data being retained, shared, regenerated, or otherwise made accessible to entities or persons that are not in compliance with the DUA.
    - Some commercial entities may offer an "opt-out" clause in the terms of use for their models, allowing users to decline the right of the entity to retain the data for training and other purposes. **An opt-out clause does not constitute sufficient protection, and under no circumstances can this be viewed as an acceptable safeguard for sharing LITE data with these third parties.**
    - Investigators making use of computational resources such as Microsoft Azure, Google Cloud, Amazon Web Services, Runpod, or other computational services for the purposes of training AI models must take care to review the terms of use for the service to ensure that their workflow is secure.

- **Public release of models trained using LITE data**
    - The use of LITE data in training models is both permitted and encouraged, provided that the process is carried out in compliance with the DUA and as outlined above. However, investigators who intend on making the weights of a trained model publicly available should consider whether the model could be used to easily reconstruct parts of the LITE data set.
    - LITE prohibits sharing of participant-level data, even if it is processed or altered and lacks LITE subject codes. All participant-level data generated by LITE can only be distributed via a LITE-approved repository (or other approved repository, as designated by the LITE program). As such, any model that has been trained using participant-level data may only be shared through MJFF-approved methods. Individual investigators who have derived participant-level data based on LITE data can request for their data to be archived and shared with the research community by contacting MJFF Data Resources at resources@michaeljfox.org.
    - This precaution is particularly important in the case of large language models and other overparameterized generative models. Numerous studies have demonstrated that it is possible to extract training examples from these models, and investigators should keep this fact in mind.

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I understand that failure to abide by these guidelines will result in the termination of my LITE data access. Furthermore, LITE reserves the right to pursue damages for actions which violate LITE guidelines.