International Neuromodulation Registry Data Use Agreement

I request access to data stored in the International Neuromodulation Registry (INR) for scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

1. I will receive de-identified data and will not attempt to establish the identity of or attempt to contact any of the INR subjects.
2. I will not attempt to make direct contact with INR PIs or staff at sites concerning the specific results of individual subjects.
3. I will not further disclose these data beyond the uses outlined in this agreement and my data use application.
4. I understand that redistribution of data in any manner is prohibited.
5. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this Data Use Agreement by registering with the INR database and agreeing to these terms.
6. I will accurately provide the requested information for persons who will use these data and any planned analyses using these data.
7. I will respond promptly and accurately to annual requests to update this information.
8. To promote further scholarly productivity, I acknowledge that INR study leadership may request that I submit data generated from analyses of INR data upon completion of my analyses. I understand that INR study leadership may choose to incorporate raw data into the INR database.
9. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.

If I publish abstracts using any INR data, I agree to the following:

10. I will cite INR as the source of the data and the INR funding sources in the abstract as space allows.
11. Acknowledgement of INR will not be cited in the author block of the abstract.

If I publish manuscripts using and INR data, I agree to the following:

12. On the by-line of the manuscript, after the named authors, I will include the phrase "the International Neuromodulation Registry*" with the asterisk referring to the following statement and list of names:

    Data used in preparation of this article were obtained from the INR database (website). As such, the investigators within the INR contributed to the design and implementation of INR and/or provided data but did not participate in analysis or writing of this report. A complete listing of INR investigators can be found at: (webpage within Registry).

13. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the INR personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below, however inclusion of some variation of the language shown below is mandatory.

    Data used in the preparation of this article were obtained from the International Neuromodulation Registry (INR - website). The INR was launched in 2018 and is led by Principle Investigator Christopher R. Butson, PhD. The primary goal of the INR is to improve the collective

ability of physicians and researchers using studying neuromodulation therapy to predict the outcomes of the therapy. This goal is supported by curating disparate datasets and increasing the statistical power of analyses by combining datasets from different institutions and centers. For up-to-date information, see (website).

14. I will acknowledge funding by the INR in the support acknowledgement section of the manuscript using language similar to the following:

    *Data collection and sharing for this project was funded by the International Neuromodulation Registry (INR) (NIH Grant ######, NSF Grant #######). The INR is funded by the NIH National Institute of *****. The INR is housed at the University of Utah in the Scientific Computing and Imaging (SCI) Institute.*

15. In the works cited section of the article, I will cite the individual datasets used in the following format (variations according to journal style guides are expected, but the basic information must be present).

    [dataset] Researchers who generated the data; Year submitted to the INR; Dataset title; Data Repository or Archive; Version; Persistent identifier.

    For example: [dataset] Hedges, D.M., Hegman, J.C., Bowles, A.E., Butson, C.R.; 2018; University of Utah Interleaving Study; International Neuromodulation Registry; Version 1; INR_0001

16. I will submit all manuscripts to the INR Data and Publications Committee prior to submitting to a journal. This review will not be a scientific review but is intended to ensure that items 8-15 above are correctly implemented.
17. I will comply with the INR Intellectual Property (IP) policy that states:
    a. Rights to any non-INR IP ("Background IP") that a researcher uses in analyzing or manipulating INR data, information, biospecimens, materials or results ("Study Materials") may not be claimed by any other researcher or institution
    b. No researcher or institution may claim any IP rights to any Study Materials or inventions arising out of the Study Materials
    c. Researchers who publish or present analyses of Study Materials will make these freely available without charge to the research community through the INR website, when not prohibited by journal copyright terms and conditions
18. I will do my best to ensure that Investigators who utilize INR data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement and will report any use or disclosure of data that does not comply with the guidelines established by this Agreement within 15 days.

IMPORTANT NOTE: The INR Steering Committee is committed to the betterment of society through scientific and translational research. Therefore, it is the policy of the International Neuromodulation Registry to make data available to investigators as quickly as possible. However, data analysis for this project is expected to take years as methods for analysis evolve. Thus, I understand that any processed data that I download may be preliminary and the results may change as new methods of analysis are implemented. I am aware of the limitations of these data prior to using them for scientific purposes and that future results may change as additional data become available. I will familiarize myself with the

analysis methods so that I am aware of the limitations of these data prior to using them for scientific purposes.

Finally, because "preliminary data" will be base, in the event that I download data from the INR data base 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 within the publication. I understand that failure to abide by these guidelines may result in termination of my privileges to access INR data. [Investigators will be asked to sign this agreement electronically at www.INR-info.org/data]

*Based on the Michael J. Fox Foundation Parkinson's Progression Markers Initiative (MJFF PPMI) Data Use and Sharing Agreement (http://www.ppmi-info.org/documents/ppmi-data-use-agreement.pdf) and the Alzheimer's Disease Neuroimaging Initiative (ADNI) Data Sharing and Publications Policy (https://adni.loni.usc.edu/wp-content/uploads/how_to_apply/ADNI_DSP_Policy.pdf).