

Fox Insight Publications Policy

Guidelines for Publications Utilizing Fox Insight Data

Introduction

Publication of results relating to and resulting from Fox Insight (FI) Data is a major goal of the FI Steering Committee (SC) and the study sponsor, The Michael J. Fox Foundation for Parkinson's Research (MJFF). This document outlines Fox Insight's policies for publications and required citations for publications, abstracts and posters utilizing Data. The term "Data" for purposes of this Fox Insight Publications Policy is defined as 1) phenotypic and other data collected in the Fox Insight Study ("FI Data") and 2) a limited set of de-identified individual level genetic data consisting of single nucleotide polymorphisms (SNPs) variants and/or de-identified individual level genetic data and/or summary statistics regarding genotypes or quality procedures (collectively, the "23andMe Data") which is owned by 23andMe, Inc. and has been licensed to MJFF from 23andMe. This Data is accessible to researchers through the Fox Insight Data Repository upon agreeing to and signing the Fox Insight **Data Use Agreement(s)**.

The intent of this policy is to ensure that:

- Data is accessed and cited appropriately
- FI study participants are recognized for their contribution to research
- FI Committee and Study Core members are recognized for their effort in study design, and acquisition, analysis and interpretation of data
- FI publications will be tracked to develop a complete record of the findings resulting from the Data analyses.
- FI publications are open and available to the public free of charge. Further information is provided below.

FI Data and Publication Committee

The Fox Insight Data and Publication Committee (DPC) acts as the primary body overseeing the publication of Data. The DPC functions to set and periodically review the Fox Insight Publication Policy; facilitate the publication of Data; and mediate any disputes arising over the publication/presentation of FI results featuring the Data.

A "publication" is defined as any manuscript, abstract, poster, slide deck or other disclosure or public use of the Data (including posting of such data on a website).

Publication Categories

It is anticipated that there will be two categories of FI publications:

I. STEERING COMMITTEE-ENDORSED PUBLICATIONS:

The Fox Insight Steering Committee sets Fox Insight’s overall study design by advising on the study protocol, schedule of activities and patient engagement methodology. Steering Committee members are responsible for generating and prioritizing new research topics and publishing key analyses conducted in collaboration with the FI Statistics Core.

Steering Committee-Endorsed Publications are defined as publications identified and developed by the FI Steering Committee (SC), and publications developed by Study Cores and Working Groups which have been reviewed and endorsed by the Steering Committee. These publications may include but are not limited to characterizing the study’s subject population and unique, virtual infrastructure. Examples include publications detailing cohort characterization, baseline or longitudinal FI data trends, recruitment and retention tactics or study feasibility. A list of planned SC-endorsed publications can be found on the [FI website](#).

Steering Committee-endorsed publications require use of the FI data repository at LONI as the exclusive source of FI study data; and collaboration with the FI Statistics Core on data analyses. Collaboration is defined as either the Stats Core conducting the analysis, or reviewing and approving an analysis plan that a separate, qualified stats core will execute. Please note the Statistics Core will not replicate analyses already completed.

II. ALL OTHER PUBLICATIONS

It is expected that researchers outside of the study Steering Committee and Cores will conduct research and seek to publish analyses using Data. These individuals are encouraged to publish novel scientific findings that result from their research using Data.

Authorship and Acknowledgements

Regardless of what subset of data is used in analyses or publications, as part of the Fox Insight Data Use Agreement, researchers will be asked to agree to the following:

Authorship: All publications will follow ICJME authorship criteria to reflect the contributions of all authors. As outlined on the ICJME website, criteria for approval are:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Acknowledgements: All publications utilizing Data or 23andMe Data will acknowledge FI funding support, the Parkinson’s community and 23andMe research participants and employees by including the following within the manuscript:

“The Fox Insight Study (FI) is funded by The Michael J. Fox Foundation for Parkinson’s Research. We would like to thank the Parkinson’s community and 23andMe research participants and employees for making this research possible.”

Publications that do not utilize 23andMe Data will acknowledge FI funding support and the Parkinson’s community by including the following within the manuscript:

“The Fox Insight Study (FI) is funded by The Michael J. Fox Foundation for Parkinson’s Research. We would like to thank the Parkinson’s community for participating in this study to make this research possible.”

Data access: All publications will report the date of access to the Data by including a version of the following within the manuscript:

“Data used in the preparation of this article were obtained from the Fox Insight database (<https://foxinsight-info.michaeljfox.org/insight/explore/insight.jsp>) on DD/MM/YYYY. For up-to-date information on the study, visit <https://foxinsight-info.michaeljfox.org/insight/explore/insight.jsp>.”

Open access: Publications will be made freely available without charge to the research community through the FI website, when not prohibited by journal copyright terms and conditions.

For Steering Committee-endorsed publications only, in addition to the named authors, “and the Fox Insight Study (FI)*” will be written on the author line with an asterisk referring to a list of FI Committee and Core members. The **Committee and Core Acknowledgement list** must be included as an appendix to ensure all Study Committee and Core Members are acknowledged. The complete FI Committee and Core list can be found [here](#).

Free Public Access to FI Publications

The intent of the FI publication policy is to provide for open, free, public access to analyses of FI data. Publications authored by the Steering Committee shall be published in an open-access journal or in a hybrid open access journal as a fully open access article, and/or posted to an open-access repository under the Creative Commons Attribution 4.0 Generic License (CC BY 4.0) or an equivalent license. BioRxiv (“Bio-Archive”; <http://www.biorxiv.org/>) is the preferred repository for FI publications. Publication under other, more restrictive licenses (e.g. CC-BY-SA) may be considered on a case-by-case basis. Under extraordinary circumstances, authors may request an exception to this policy by applying to the FI Steering Committee.

Authors may submit requests to FI’s sponsor, MJFF, to cover the fees required by a publisher to effect publication on the aforementioned terms. Requests for cost coverage of publication fees must be made prior to the author paying fees to the publisher. Requests for retroactive reimbursement for open access fees may be considered by MJFF on a case-by-case basis.

External users of FI data are also strongly encouraged to publish results in open-access journals or in a hybrid open access journal as a fully open access article, and/or post to open repositories.

Other Publication Requirements

All publications including or resulting from use of the 23andMe Data will additionally comply with the following requirements.

1. The publication may only include summary statistics for up to 10,000 SNPs obtained from the 23andMe Data.
2. The publication must be published in an open-access journal or be rendered open-access through payment to the corresponding journal, or be otherwise made publicly accessible without any payment of fees by any individual seeking access to the publication, such as publishing a preprint or postprint of the publication in a reputable archive.

Publication Review Process

The DPC and MJFF will conduct an administrative review of publications to confirm proper use of acknowledgment and data access statements. The DPC and MJFF will not review publications for scientific quality or clinical accuracy, trusting that the peer-review process is the best way to judge the objective quality.

As per the [Fox Insight Data Use Agreement](#), investigators are reminded that they must submit manuscripts to the FI DPC for administrative review 2 weeks *prior* to submission to a journal and abstracts 1 week *prior* to submission to a conference. Submissions to the DPC can be made via the [FI website](#). [All submissions and manuscripts that include or derive from use of the 23andMe Data may be shared with 23andMe.](#)

1. Review is guaranteed within specified time frames. In the event that publications are developed after the formal FI DPC has dissolved, review will be handled internally by MJFF staff.
2. Upon publication of a manuscript, abstract or poster, the final, approved version and the complete reference must be submitted to the [FI DPC](#) for record keeping (and may be shared by FI DPC with 23andMe).

Unusual Situations

It is expected that the preceding paragraphs of this publication policy will cover the majority of users of the Data. We anticipate that investigators will follow these guidelines in good faith and that most analyses will be of reasonable quality. However, if we do encounter what we consider in our sole discretion to be unusual circumstances, we will take the following actions:

1. Egregiously Poor Manuscripts and abstracts. If a review of a proposed manuscript reveals that it is egregiously poor in terms of language, writing or sensible substance, the DPC can recommend to the authors that it not be submitted without significant revision. If the authors choose to submit the manuscript anyway, the DPC

will have the option to: 1) request that the authors publish a statement to the effect that while Data were used, the FI DPC did not find this manuscript of sufficient merit to warrant submission for publication, and/or 2) revoke privileges to use Data in the future.

2. Fraudulent Use of Data. Open access using only online registration raises the possibility that individuals could obtain access to data under false pretenses. It is possible that the data be used inappropriately. Should the DPC discover an attempt to publish using Data obtained fraudulently, the user will be sanctioned through DPC communication with them or their supervisors and DPC may take any other immediate steps to cure or end such inappropriate use of the Data, including discontinuing the user's data access and/or reporting the violation.
3. Journal Objections. It is possible that journal editors may object to the group acknowledgment format with the caveat that those FI names credited have participated in study design and data acquisition but not participated in the analysis and writing of the paper. The DPC can authorize exceptions to the acknowledgement policy or can negotiate with journal editors as needed on a case-by-case basis.

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