myMPN Data Use Policy

Access to data from the MPN Research Foundation's myMPN patient registry (myMPN) by academic or industry researchers must be approved by the MPN Research Foundation Registry Steering Committee (RSC). The MPNRF aims to ensure that data from myMPN and the resulting research findings yield valuable insights into the diagnosis and progression of Myeloproliferative Neoplasms (MPNs). To evaluate requests and ensure that proposed uses are consistent with MPNRF’s goals and participants’ authorized uses of their data, the MPN Research Foundation (MPNRF) requires that a Data Request Form (attached to this Policy) be submitted to request access to/use of myMPN data.

Data requests will be reviewed as they are received. We anticipate that the review process for data requests will take approximately eight weeks after receipt of a complete Data Request Form. Following review of a complete Data Request Form, the MPNRF will inform the researcher whether the data request has been approved. If approved, MPNRF will provide an anticipated timeline for providing the data and an estimate of the costs (if any; see Section 4 below) of fulfilling the request.

Before myMPN data can be released, proof of Institutional Review Board (IRB) approval (if required) of your proposed project must be sent to the MPNRF (myMPN@mpnrf.org). In addition, your institution or company must enter into a data use agreement with the MPNRF. We must also be assured that the following issues are addressed. The MPNRF reserves the right to deny a request to access myMPN data in its sole discretion.

1. Protection of Participant Confidentiality

The MPNRF releases de-identified/anonymized data unless identifiable data (which may include data elements such as zip code or birth date) is imperative for the research project, as verified by the RSC based on its review of the protocol and other information submitted. Please note that identifiable data may be released and used only as permitted by participants via their individual myMPN privacy settings (as described in this document), the reviewing IRB, and applicable law. More information about myMPN privacy settings, as well as the myMPN Privacy Policy, the Genetic Alliance PEER Privacy Policy, Genetic Alliance PEER Terms of Service, Private Access Privacy Statement, and Private Access End User License Agreement applicable to the myMPN registry platform are available at www.mympn.org/privacy.

2. Responsible Use of myMPN Data

The MPNRF RSC evaluates data access requests based on whether research questions are appropriately focused, the research is feasible and of scientific merit, the variables of interest are well-defined, and the limitations of the data within myMPN are recognized. A list of myMPN data fields in excel format will be provided upon request.

Researchers are encouraged to submit articles/abstracts describing their findings to US and international research and industry meetings and publications. Completed work will also be considered for presentation at upcoming MPN Research Foundation Annual Roundtables. Completion of a manuscript for submission to a peer-reviewed journal within 2-3 years of receipt of the data should be a

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goal. It is in researchers’ best interest and in the interest of the MPN community that researchers complete their analyses and interpretation of the data as quickly as possible. If a researcher requests myMPN data to pursue a project similar to a previously-approved project, MPNRF will inform the new researcher that a similar data request has been fulfilled in the past so that the researcher may revise his/her request.

If a researcher wishes to expand upon the scope of work regarding an approved project or would like to perform related analyses that require additional data, please email a request to myMPN@mpnrf.org.

3. Publication Policy

Prior to the submission of abstracts, poster presentations, or manuscripts, a copy should be sent to myMPN@mpnrf.org for review by MPNRF or RSC members. We request 30 days to review manuscripts and seven days to review abstracts for compliance with this policy and the terms of the Data Use Agreement. MPNRF may propose revisions to manuscripts and abstracts as may be needed to comply with this policy and the Data Use Agreement, and the researcher and MPNRF will cooperate in making such revisions prior to submission for publication. Once the abstract or manuscript is accepted by a scientific organization or journal, one copy of said paper, or a suitable description of the exhibit, shall be forwarded to the MPNRF on notice of such acceptance, together with the name of the publication or the organization accepting it and the time and place of the scientific meeting.

In addition, researchers may consult with members of the RSC on any potential publications resulting from use of the requested data as to whether the interpretations and conclusions of the authors are accurate and consistent with the scientific objectives initially stated in the proposal.

When abstracts, exhibits, invited papers or manuscripts are prepared using myMPN data, the work must include the following acknowledgement:

The authors would like to thank the MPN Research Foundation for the use of myMPN patient registry data to conduct this study. Additionally, we would like to thank participating patients and care providers for their contributions to myMPN, which make this research possible.

The MPNRF requires that no individually identifiable information from myMPN be included in publications or other written documents arising from an approved project. Data must be presented in the aggregate. All tables generated from registry data should include a patient count of five or more in each cell.

If access to myMPN data used to support a publication is requested, please direct such requests to myMPN@mpnrf.org.

4. Resources and Costs

a. The MPNRF may reject data requests that cannot be fulfilled with MPNRF’s available resources (e.g., staff time, technical resources).

b. Academic Researchers: If substantial data preparation is required to fulfill a data request from an academic researcher, the MPNRF may charge the researcher to cover costs of preparation of data or data analyses. MPNRF will provide a researcher with an estimate regarding such costs at the time of approval of a data request, and such costs and payment details will be set forth in the applicable data use agreement between MPNRF and the researcher’s institution.

c. Industry Researchers: MPNRF will charge commercial entities for all data preparation costs. MPNRF will provide a researcher from a commercial entity with an estimate regarding such costs at the

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time of approval of a data request, and costs and payment details will be set forth in the applicable data use agreement between MPNRF and the commercial entity.