Standard Operating Procedures for use of the Phenotype Recording Instrument and the Rockefeller University Bleeding History Phenotyping Symptom Repository (RUBHPSR) by investigators outside of the Rockefeller University

1) Interested investigators will contact Dr. Yupu Liang (liangy@rockefeller.edu), whose contact information will be available in relevant publications and on the Phenotype Recording Instrument (PRI) website.

2) Dr. Liang will provide investigators with the url to the PRI (https://bh.rockefeller.edu/prat/), as well as a test login that will permit them to evaluate the instrument/questions. This test login will be flagged as unsuitable for inclusion in analyses by marking it with Site Id „111."

3) If the investigator remains interested in using the PRI after testing the instrument, she/he will supply Dr. Liang with:

- The number of Protocol IDs required and a name to associate with each Protocol ID. Protocol ID is a unique identifier used to identify different protocols conducted at a single site.

- The number of Administrator IDs required and a name to associate with each Administrator ID. Administrator ID is a unique identifier used to identify different PRI users and to define their level of access to the PRI and PRI Reports. Administrator ID is only a label used to identify users within the PRI and should not be confused with the investigator.

- The number of Site IDs required and a name to associate with each Site ID. Site ID is a unique identifier used to identify different institutions and/or locations where the PRI is to be used.

- If the investigator subsequently requires further Administrator and/or Site IDs, they will be supplied upon request.

The PRI team will generate the requisite IDs and a password for each Administrator ID and supply them to the investigator. Dr. Liang will maintain a log linking Sites, Protocols, and Administrators with their respective IDs and a duplicate log will be maintained by Suzanne Rivera in a password protected computer file.

4) It is possible that some investigators will choose to modify the instrument to suit the needs of specific studies, or will choose to use only certain questions or question sections. In such cases, specific arrangements will be formalized with the Laboratory of Blood and Vascular Biology and the Rockefeller University Informatics Core on an individual basis. Modified questions and/or questionnaire sequences will be labeled with a unique Protocol ID, allowing data collected with modified questionnaires to be separately queried and/or excluded from query.

5) All data collected will be tagged with Administrator, Site, and Protocol IDs and maintained in the RUBHPSR with password-protected access for the investigator. Thus, if investigators prefer to retrieve only specific datasets, those specific records will be retrievable by filtering by Administrator, Site, and/or Protocol ID. Similarly, datasets that are not relevant to specific investigations will be excludable.

6) After Administrator ID, Site ID, and Protocol ID assignment are complete, Dr. Liangwill supply the investigator with an electronic copy of the PRI User Manual.

7) Investigators will have access to their data at any time via the PRI Reports Webpage (https://bh.rockefeller.edu/PRIreports/index.php). Data retrieval and representation utilities available from PRI Reports include:

- PRI Subject Query, which allows an investigator to query any subject as identified by the combination of UPIN, Site ID, and Protocol ID, and to generate a printable .pdf report of the retrieved record.

-PRI Database Query, which allows an investigator to query the entire RUBHPSR for all collected data, to filter these data by Site ID, Administrator ID, Protocol ID, and/or diagnosis, and to generate a downloadable Excel spreadsheet containing the retrieved records.

- Graph, which allows an investigator to query the RUBHPSR for all collected data, to filter these data by Site ID, Administrator ID, Protocol ID, and/or question category, and to display the retrieved records in a graphical format.

- Demographics, which allows an investigator to query the RUBHPSR for all collected data, to filter these data by Site ID, Administrator ID, and/or question category, and to display the gender, ethnicity, and race of retrieved records in a graphical format.

Access to PRI Reports will be restricted to investigators with a valid Administrator ID and password.

8) If the investigator would like access to the aggregated data maintained in the RUBHPSR from all participating investigators, the investigator will be required to authorize the addition of her/his own data the aggregated RUBHPSR. Conversely, if the investigator would prefer not to add her/his data to the RUBHPSR, she/he will only have access to her/his data. Investigators with full RUBHPSR access will have "Level 1 Access" to the PRI Reports Webpage. Investigators whose access is limited to their own data will have "Level 2 Access" to the PRI Reports Webpage. Level 1 Access will permit the investigator to use PRI Reports to query the entire RUBHPSR, while Level 2 Access will permit the investigator to use PRI Reports to query her/his data only. Conversely, data collected by investigators with Level 2 Access will not be available for Level 1 queries using PRI Reports (i.e., Level 2 data will be available only to the investigator(s) who collected them).

9) If an investigator agrees to allow her or his data to be added to the aggregated RUBHPSR, the investigator will be given Level 1 access to the aggregated database as soon as her or his first entry is made.

   If an investigator with Level 2 access prefers to keep her or his own data and does not want a copy of the data to be retained in a segregated dataset within the RUBHPSR, individual arrangements need to be made to insure that the procedures for deleting the segregated databases are understood and mutually acceptable.