All requests (full or partial) should be submitted two weeks before data is needed.

**Researcher’s Responsibilities**

1. Request IRB Approval
2. Submit registry data request
3. Receive written permission
4. Agree to:
   1. Use only for approved purpose/approved research questions
   2. No personal use
   3. No 3rd Party Transfer of data
   4. Cite Registry in publication or oral presentation
   5. Will not attempt to re-identify subjects
5. Manuscripts must be reviewed and have final sign-off by registry (optional for registry to require).
6. Abstracts for presentations must be reviewed and have final sign-off by registry (optional for registry to require).

**Notes:**

If requesting aggregate data (GROUP subject data only with no HIPAA or Private Personal Data - no individual subjects with identifiers) simply complete the Registry Information Request Form. All other responsibilities of Data Requester’s apply. \_\_\_\_ week notice applies to aggregate data requests

If requesting anonymized data (subject data only with no HIPAA or Private Personal Data and no identifiers). Regulatory definitions are likely to classify this as “not human subject research”.

**To publish in peer reviewed journals or present at conferences, etc.:**

Investigators who use aggregate or anonymized data are still likely to need some documentation of approval from the IRB due to editor requirements. For an official determination, contact your IRB for written confirmation.