



Proposed Rules for Research and Use of Materials

Inborn Errors of Metabolism – Information System (IBEM-IS)

- All participating centers who are entering data in the registry will have access to non-PHI.
- All publications will credit the entire group. The lead author or presenter will be the person(s) who do the majority of the work to set up the project, but they will still need to credit the Region 4 IBEM-IS Workgroup.
- Individual projects need to be reviewed/approved by a scientific advisory group then brought before the entire Region 4 IBEM-IS Workgroup for final approval.
- There are two groups of data: registry data only (self-contained), and a cohort of data obtained through the use of the registry (expanded data).
- The Region 4 logo should be included on all electronic presentations and materials.