



# IMPROVECARENOW™

## **ImproveCareNow Data Policy**

A primary goal of [ImproveCareNow](#) (ICN) is to create a community of patients, families, clinicians, and researchers working together to maximize the likelihood of finding treatments and cures for children with Inflammatory Bowel Disease. Fundamental to reaching this goal is establishing an open approach to sharing data, a strategy advocated, and often required, by many funding agencies.

The ImproveCareNow Data Management Team is charged with quickly supplying data sets to investigators conducting research projects that have been approved by the ImproveCareNow Research Division. The ImproveCareNow Data Management Team does not have oversight of what constitutes an approved/approvable research project. Responsibility for these decisions lies with the ImproveCareNow Research Committee.

All participating ImproveCareNow sites (current and future) as well as qualified researchers using data in the Outcomes Registry must adhere to the following policies:

- Take appropriate steps to maintain data security (i.e. data cannot be downloaded onto laptop, desktop, or flash drive, etc.)
- May not transfer or distribute data
- May not attempt to re-identify any individual patient in the data, or use the data in a manner that creates harm to any individuals (such as exposing them to insurance or employment discrimination).
- May not receive a full dataset that includes all variables. However, they may use only the data required for the projects proposed and approved by the ImproveCareNow Research Committee. No additional projects may be undertaken without subsequent Research Committee approval.
- Expected to re-contribute knowledge to the Network by re-depositing derived data, cleaned data, or knowledge gleaned from the data as appropriate.
- Must provide access to software and documentation for any computational research so that it is reproducible.
- ImproveCareNow must be appropriately acknowledged within a manuscript as the data source as well as included in the title.