

## CRI and HIRO Guidance on the NIH Data Management and Sharing Policy

On January 25, 2023, the National Institute of Health (NIH) instituted a policy requiring investigators to provide detailed data management and sharing plans to ensure data is available to other researchers in forms organized to facilitate reuse and reproducibility while protecting sensitive and restricted data.

The Center for Research Informatics (CRI), in partnership with Biological Science Division Information Services (BSDIS), is the only approved provider of data, storage, and computing facilities for data generated or derived from the patients in our health system,<sup>1</sup> and the CRI is the only institutionally approved honest broker for non-imaging clinical data generated or derived from the patients in our health system<sup>2</sup>. Similarly, the Human Imaging Research Office (HIRO) is the only institutionally approved provider of medical image data generated or derived from patients in our health system<sup>1</sup>, and the HIRO is the only institutionally approved honest broker for imaging data generated or derived from the patients in our health system<sup>2</sup>. These data are considered sensitive and restricted and are subject to additional privacy laws and institutional policies and procedures. The CRI, HIRO, and BSDIS will help researchers who use this data type meet the requirements mandated by NIH while providing additional resources that uphold institutional policies and procedures.

Additionally, we can assist researchers in every stage of the research data lifecycle, including consultations with the writing of data management and sharing and data security plans, as well as implementing them on CRI systems.

Our provided storage infrastructure is designed to provide a high level of security and meet the stringent requirements defined by most grant applications. All data is backed up to a tape library located in a separate data center from the primary data storage systems. Our storage and computing infrastructure give users peace of mind that professionals safeguard and manage their data.

- Our professional teams can work with researchers to collect, administer, store, and analyze data on CRI or BSD IS systems and will provide guidance with formatting stored data for transmission to on- or off-campus long-term repositories as applicable.
- Our professional teams can work with researchers to curate data and can provide guidance on data management to meet the requirements of the NIH, NSF, and other agencies so that data is organized for easy searchability, indexing, and cataloging.
- Our professional teams can develop data access portals for different labs and groups.
- The CRI (in partnership with the HIRO when appropriate) can work with researchers to de-identify datasets to protect the data while maintaining the shareability of this data.
  - *Note: Researchers must consult with CRDW professionals before de-identifying data generated or derived from patients in our health system and must have a data sharing or use agreement in place before sharing, regardless of data type (i.e., identified, limited, or de-identified)*
- The CRI **will not** maintain version control procedures for datamarts operated by the Clinical Research Data Warehouse (CRDW) but **will** guide researchers with best practices.
  - *Note: Exceptions can be made but will require budgeting for services prior to grant submission.*

To obtain CRI consultation, please submit a request [here](#) or email [cri@bsd.uchicago.edu](mailto:cri@bsd.uchicago.edu)

To obtain HIRO consultation, please submit a request via email [hirohelp@bsd.uchicago.edu](mailto:hirohelp@bsd.uchicago.edu)

To request BSDIS resources, please submit a request [here](#)

Additional information on services provided by CRI can be found [here](#).

#### **University of Chicago Resources:**

- Library – <https://guides.lib.uchicago.edu/datamanagement/nih-dms>
- University Research Administration (URA) – <https://ura.uchicago.edu/page/nih-2023-data-management-and-sharing-policy-dms-policy>
- Data Management and Sharing listserv – [datasharing@uchicago.edu](mailto:datasharing@uchicago.edu)
- Data Management Plan Tool - <https://dmptool.org/plans>

#### **Funding Agency Resources:**

- NIH Guide for Writing data management and sharing plans - <https://sharing.nih.gov/data-management-and-sharing-policy/planning-and-budgeting-for-data-management-and-sharing/writing-a-data-management-and-sharing-plan>
- NIH Cost Estimation Tool - <https://nda.nih.gov/contribute/contribute-data.html#cost>

#### **BSD Policies:**

<sup>1</sup>CR\_POL\_116 Access to University of Chicago Health System data by the University of Chicago or University of Chicago Medical Center employees for RESEARCH <https://voices.uchicago.edu/ocr/clinical-research-policies/>

<sup>2</sup>CR\_POL\_117 Creation of De-identified Data or Limited Data Sets for Research Purposes <https://voices.uchicago.edu/ocr/clinical-research-policies/>