Galter Health Sciences Library & Learning Center

Forging Data Connections: A New Clinical Data Retrieval and Management Program

By: Sara Gonzales, Data Librarian

Advances in clinical data warehouse architectures, clinical coding standards, and HIPAA-compliant access and dissemination methods have made accessing data from sources like <u>Northwestern Medicine's Enterprise Data Warehouse</u> (NMEDW) a more vital piece of the clinical research puzzle than ever before. Yet these same advances often create barriers for researchers requiring access to these resources in the form of the advanced technical knowledge necessary to meaningfully access them. Clinical research data education and training have been identified as crucial needs for today's researchers, yet can be difficult to meet due to the many other competing demands for time.

To meet these needs, <u>Galter Health Sciences Library and Learning Center</u> has partnered with the NMEDW through a grant from the <u>Network of the National Library</u> <u>of Medicine Greater Midwest Region</u> to create a data retrieval and management training program for clinical researchers. The goal of this program is to meet the end-to-end training needs of researchers as they work to access, use, and re-use clinical data.

The foundation of the program will be a series of trainings about how clinical data is collected, stored, and retrieved, and best practices for managing and manipulating data. Researchers will learn how to identify a population of interest in the NMEDW and how to create a workflow of data query and retrieval using SQL. The program will also promote increased collaboration between researchers and data analysts, through which expertise can be shared and partnerships on research projects can be reinforced. In the final phase of the program, researchers will learn about local tools for preserving workflows and enabling the reproducibility of NMEDW search queries, research reports, and other research documentation. These tools include the next-generation research data management system InvenioRDM, currently in collaborative development by <u>CERN</u>. Galter Library, and several other international partners. This system will soon form the new back-end architecture of Feinberg's institutional repository.

Classes are currently being offered through Galter Health Sciences Library in the area of <u>Data Management</u> and include *Best Practices in Research Data* Management and Sharing and Cleaning Spreadsheet Data with OpenRefine. Future offerings will include Understanding and Implementing the FAIR Data Principles, Introduction to Clinical Databases and SQL, and Sharing and Preserving Biomedical Data.

Daniel Schneider, Manager of Research Analytics for the Northwestern Medicine Enterprise Data Warehouse, is a partner on the training program and is excited by collaboration opportunities that the training program offers. "One of the largest gaps I currently see in the translational research landscape is the lack of a coordinated technical training program connecting the technical expertise to the clinical expertise needed to fully understand and execute complex health care analyses. As each group becomes more familiar with each other's terminology and methodology, these groups can become far more effective collaboration, reproducibility, storage, and long-term preservation."

Kristi Holmes, PhD, director of Galter Library and professor of <u>Preventive Medicine (Health and Biomedical Informatics)</u> and <u>Medical Education</u>, is also thrilled about the grant. "This innovative new program will support our investigators as they leverage the incredible data resources of the NMEDW in support of research, clinical, operational, and educational priorities. We're thrilled to partner with the NMEDW team and look forward to this unique opportunity to support and advance data-driven discovery and innovation."

For more information on the data retrieval and management training program for clinical researchers, contact project lead Matthew Carson at <u>matthew.carson@northwestern.edu</u>. For general data management help, education, or to submit a help request, visit the <u>Galter DataLab</u> or <u>email the DataLab team</u> today.

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