RE-250159-OLS-21, North Carolina Central University

LB21-FY21 - NC Central University (NCCU) School of Library and Information Science (SLIS)

Title: Storing and Accessing Healthcare Data, Algorithms, and Programs in Libraries (Training)

Health Informatics researcher and experienced course developers from the School of Library and Information Sciences (SLIS) at NC Central University seek a 16-month planning grant to develop a pilot course and deliver online learning materials for a sustainable training institute so that librarians and information professionals can build and maintain repositories and databases for Mobilizing Computable Biomedical Knowledge (MCBK). With affiliated partners and resources, they would design and develop an open education resource (OER) platform for the pilot and future project. The National Library of Medicine (NLM) is already working with MCBK experts from the Michigan School of Medicine and Duke University. However, few LIS professionals and graduate students are familiar with the protocols and models for storing biomedical research software and data. The training will include demos, exercises, and hands-on labs with protected electronic health records and medical data for LIS students to learn computer and database processes for storage and access using meta-data and reference models, phenotypes for machine learning, and how to maintain healthcare data repositories.

Statement of Need: By building relationships and skills early, the LIS field can impact information policy and digital access decisions as they are being made rather than having to react to poorly implemented policies or metadata structures put in place by decision makers who are more focused on the technology than on information itself. As NLM director, Dr. Patricia Flatley Bennan has said, we need models with rigor, reproducibility and reuse. Federally funded data research collections are accessible, but data and programming need to be shared. The standard approach in libraries towards nomenclature, format, and transmission is not sufficient. LIS needs to prepare to lead in new directions that support community healthcare and collaboration to archive and store software and data as well as printed, text-based and graphical objects. The code and data summarized in research publications needs to be accessible for validation of software and data analytics. The IMLS can support leadership who will improve ease-of-use for research data in biomedical research and other fields.

Project Goals: For many years the Library and Information Science (LIS) world has become intimately involved with the information needs of medical and healthcare professionals, and Health Informatics programs have been implemented in a variety of LIS schools. As research has found, "little attention has been paid to forecasting the information resources and services that researchers, specifically, will need" (Cain et al., 2016; doi:https://doi.org/10.5860/crl.77.5.595). Whereas, LIS has begun to lose reference and knowledge management positions to more IT-related workers, this grant would address the need directly by involving LIS professional on the ground floor as MCBK repositories, protocols for software and data are being designed and implemented. LIS professionals can have an early seat at the table to keep our competitive edge within the data archives and repository field. By building an online training curriculum with health informatics experts from around the country, this pilot and project will capitalize on the wealth of knowledge available within the LIS academic world. The grant would support the advancement of theory and practice in biomedical informatics while developing leaders in computable knowledge storage, access standards and tools across LIS disciplines and would address specific information needs of the medical and healthcare community currently as well as data needs in the future. Equipping LIS professionals with skills and tools in software and data storage will support the learning health systems objective that every decision affecting the health of individuals and populations should be informed by the best knowledge available.

Project Design and Deliverables: The project will start on August 1, 2021, and end on December 31, 2022. The project leaders will work with health informatics specialists and librarians as partners and resources. NCCU graduate research assistants will help collect MCBK materials and data structures. The pilot training will be held in early 2022 and be broadcast remotely. There are four phases:

1. August 1 – October, 2021 – Develop course plan and OER materials for 5-day pilot based on qualitative, grounded research with partners and experts in MCBK, digital libraries and health data.

2. October, 2021 – February, 2021 – Advertise pilot course via social media to SLIS alums, LIS schools and research companies; recruit 20 attendees who will be given stipends; hold pilot study training (in January or February); provide social media-based communications during pilot; observe the one week's training and collect data from recordings and follow-up questionnaire and focus groups.
3. March, 2022 – May, 2022 –Analyze learning data from observations, social media, and focus group; prepare collaborative reports on pilot results and future project design for stakeholders.
4. June, 2022 – December, 2022 - Present pilot results and future project plan to July MCBK conference in Bethesda at NLM. Summarize learning project in article for an LIS journal (*JELIS*) and complete OER documents and course materials for the sustainable, online training institute project.

Diversity Plan: As a prominent HBCU school, NCCU's SLIS will be able to recruit librarians and information professionals among recent and interested MLS and MIS students who represent diverse ethnical backgrounds. Health disparities are prevalent in economically challenged communities of color. Ethnically diverse students in the pilot and future project will be able to support research into the application of computer programs and biomedical informatics to reduce disparities. The pilot and future institute will promote the inclusion of diverse patients, providers and researchers using decision support systems, machine learning, and AI to improve diagnoses and chronic care management.

Broad Impact: Promoting healthcare research in libraries has been a national concern for many years. A Health Information Initiative from the National Network of Libraries of Medicine (NNLM) stated in 2018 (http://www.ala.org/pla/initiatives/healthliteracy) "access to current and reliable health information is imperative for the well-being of all Americans …." Data that is transparent in format (or phenotype) and formulas or algorithms that can be repeated are needed to develop an effective learning health system where research data are reliable and verifiable. A LHS depends on collaboration and trust if healthcare data are to be shared. MCBK principles support skills that make sure databases are interoperable with metadata and API access, and follow standards to support the preservation of information and data. The proposed pilot course and project institute with sustainable, online training about MCBK and health data supports continuing education goals for library and archive professionals to provide access to diverse digital content and to create new theories and practices for the digital infrastructures of the 21st century.

Key Personnel: *Dr. Deborah Swain* (Project Director) contributes research and expertise in knowledge management (KM), data analytics and health informatics; she serves on MCBK workgroups for trust and sustainability. *Dr. Chris Cunningham* (Co-Project Director) has CIO and program director experience in business and academics; he teaches graduate MLS courses in management and leadership.

Collaborative Partners: Dr. Charles Friedman, LHS department chair, and Rachel Richesson, Michigan School of Medicine; health informatics, LIS, and data analytics consortium partners in NC (Duke, UNC-Chapel Hill, East Carolina University, UNC-Charlotte and Wake Forest) including Javed Mostafa at UNC-Chapel Hill; LIS, KM and HI experts at Arizona (Jerry Perry), the University of South Carolina (Feili Tu-Keefner) and North Texas University (Suliman Hawamdeh, Ana Cleveland and Jody Philbrick); NIH data experts consulting at the NLM: Rebecca Goodwin and Dawaei Lin; Robin Ann Yurk at MD Yurk.

Estimated Budget: The budget request for this planning grant covers: (1) 1 in-state graduate students' tuition and fees for four semesters estimated @ $5195 per semester plus fringe is **$21,040**; (2) stipends for 15 LIS professionals to attend 1 week of pilot training via WebEx at NCCU for 1-hour CE credit @ $1500 each for **$22,500**; (3) stipends to 6 partners for contributions estimate @ $1000 is **$6,000**; (4) 2 yrs summer research support for project leader (@5,593 per year with fringe) and co-leader adjunct (@$4500 per year with fringe) to develop course plan, learning materials and publications is estimated at **$20,186.** TOTAL REQUEST is for **$93,432** (no cost sharing required; indirect costs adjustment added and fringe included)