

Research Data Management Readiness at Uganda Cancer Institute

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Abstract

The study explored research data management readiness at the Uganda Cancer Institute. Its objectives were to; establish the state of research data and the institutional readiness for research data management practices. The case study applied a survey method using a questionnaire modified from the Data Asset Framework and the Community Capability Model Framework. The respondents were 60 staff members at different professional levels purposively selected. The findings show massive data generated from clinical trials, and routine cancer clinics at the institute. The business processes are mainly manual except for the funded research projects which are hybrid. The existing data sets could not be quantified, but all patient-related physical data are permanently archived in the institute's registry. The electronic research data from funded projects is under the responsibility of the System Administrator and the Data Officers of respective projects. Research data management readiness assessed through collaborations was taking place and beneficial to the institute, and the technical infrastructure was robust. Findings indicate the absence of an institute-wide legal/policy framework and a substantive skills training program for staff research data management competence development. Research data management practices were intuitively executed in funded projects, the ethical requirements were embedded in the research cycle and adhered to. The study recommended emphasizing a written localised Data Management Plan for all projects submitted for approval; initiating a tailor-made RDM training program; a comprehensive RDM policy, and creating RDM awareness and interest among staff at the institute.

Keywords: Research data, Cancer, Protocols, FAIR, Research Data Management, Data Asset Framework, Community Capability Model Framework, Uganda Cancer Institute, Data Management Plan, Collaboration.