RESEARCH DATA MANAGEMENT AND RESEARCH DATA RE-USE IN UGANDA

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Abstract

The purpose of this paper was to understand the state of Research Data Management (RDM) and possible Research data re-use in Uganda. Its objectives were to examine; the current research data management practices; legal and ethical issues surrounding research data re-use and propose a strategy for developing awareness about RDM in Higher Education Institutions. Existing literature was reviewed to provide a synopsis of RDM in Uganda. As a first paper on the subject from Library and Information Science perspective, it is work in progress towards developing a deeper understanding of this evolving field of study. Findings show that, there is absence of a standardized and comprehensive RDM policy or guidelines in the country, that there is no evidence of a legal and ethical framework for research data re-use. In medical and Banana Research cluster, aspects of RDM for possible re-use are being developed. In many collaborative medical research with Europe and American Universities' protocols in place have some clauses on research data re-use but in Uganda there are restrictions that may make them impossible to apply. Furthermore, there is neither institution nor course that provides for RDM skills and there is no research data set repository in the country. Recommendations are include the following: that a curriculum for RDM be developed for inclusion in LIS at both Bachelors and Masters level of academic studies, that short courses be developed for all Researchers at every level, that an RDM plan be made mandatory for all research works and that preservation, re-use and ethical issues required should be highlighted.

Keywords: Research Data Management; Research Data Re-use; Research Ethics; Research Institutions

1. Introduction

This paper is about establishing the current state of Research Data Management (RDM) in Uganda as a basis for exploring the values accruing from Research data re-use. Its objectives were to examine; the current research data management practices; legal and ethical issues surrounding research data re-use and to propose a strategy for developing awareness about Research Data Management in Higher Education Institutions.

2. Background to Research Data Management in Uganda

Uganda is a land locked country with a population of 39 million people (World Population Prospects, 2015). The country boasts of six Public Universities and 27 Private Universities seven of which are charted Universities (MESTS, 2015). The total enrollment is about 100,000 students pursuing different courses from Certificates to Post Doctorial studies. The country in addition has over one hundred and thirty two (132) public and private other tertiary institutions

offering a diverse range of studies in; business, technical and vocational education at different professional levels usually below the degree level. In addition there are numerous profit and not for profit organizations involved in different aspects of Research undertakings for both academic pursuit and social economic transformation of the country.

In line with the desire to stream line research work and to create a one stop clearing centre for that purpose, an Act of Parliament was passed in 1990 to establish the Uganda National Council of Science and Technology (UNCST) Act (Cap 209). Among its functions, the Act seeks to:

"carry out scientific and technological research and development (R&D), to act as a clearinghouse for information on research and experimental development taking place in scientific institutions, centres and other enterprises and on the potential application of their results and protect intellectual property through appropriate patent laws and to operate a national patent office".

All research matters in Uganda are therefore coordinated nationally through the UNCST directly under the Office of the President. The Council is responsible for overseeing research work in all its diverse manifestations in the country and all persons and institutions carrying out research in Uganda are expected to register their projects with the UNCST.

In execution of its mandate, UNCST, established guidelines through which it decentralized some of its responsibilities by forming National Research Committees and approving of Institutional Research Boards/Committees. These review research proposals submitted to them and ensure their compliance to acceptable International and national research ethical standards and requirement. The Committees register such research proposal submitted and monitor their compliance with the agreed ethical issues. This is done on behalf of the Council and regularly provide reports of their activities to the Executive Director of the Council. All research Institutions and Higher Education Institutions are mandated to have functional Research Ethic Committees and or Institutional Research Committees approved by UNCST

3. Current Research Data Management Practices

Research data are valuable resources, regardless of discipline or format and require institutional policies to; protect, preserve, and ensure their future access (ASERL / SURA, 2012). Actively managing Research data is rapidly becoming a best practice within research Institutions seeking to protect both the financial investment in research, and improve transparency and reusability of scientific findings, (Kennan and Markauskaite, 2015).

In Uganda, research work is largely undertaken by public sector institutions with international collaborations and sponsorship (Ecuru, et.al, 2008). Much of the fields of research are categorized into: Medical and Health Sciences, Natural Sciences, Engineering and Technology, Agricultural Sciences and Social Sciences and Humanities in accordance with International standardization of statistics on Science and Technology (UNESCO, 1978; UNCST, 2008)). The categorization is consistence with Uganda's Vision 2040 that seek to strengthen human resources in these sectors as pre requisites for harnessing their potential for social economic transformation of the country.

Research institutions have also been categorized as: Institutions mandated to formulate and implement research policy and national level coordination; Regulatory institutions including those for Standards and Intellectual Property Management; Research Institutions – which carry out research; Training Institutions which produce the human resources for research, as well as carrying out research and Research Support Institutions – which plan and manage research activities as well as the financing and dissemination of research results.

Although all Universities and Tertially Institutions are engaged in Research, Makerere University is the oldest Higher Education Institution in Uganda with over 90 years of research experience. Over the years the University has developed a comprehensive curriculum at undergraduate and graduate levels across disciplines. In an effort to become a Research driven University, Makerere University has attracted several partners, who have immensely contributed to research development (Makerere Strategic Plan, 2008/09-2018/19). Based on current trends, the University is focusing its research agenda to be theme-driven based on a mixture of disciplinary, inter-disciplinary and multi-disciplinary research clusters. These are pursued through various collaborative initiative in addition to development of cross-cutting research facilities like; Demographic Disease surveillance sub-programs, cross-cutting biomedical laboratory and Geographical Information System laboratory.

In such situations, research data and its management increasingly becomes important and valuable. However, available policy guidelines and research working documents examined, lack the aspect of Research Data Management plans. The Curricula at the College of Computing and Information Science and particularly at East African School of Library and Information Science for different academic programs lack Research Data Management (RDM).

It is noteworthy, that Makerere University Library has a functional Institutional Repository and Digitization unit, their policies and guidelines are silent about RDM. Other Universities and Tertially institutions research guidelines accessed and examined <u>are all</u> silent on and about Research Data Management. This is an indication that no work has been done on the subject in Uganda despite great strides that have been achieved in other nations. This is the first study from a Library professional perspective and an opener for deeper understanding and consequently adoption of RDM as best practice across Research works.

3.1 Agriculture Research

The National Agricultural Research Organization (NARO) is the apex body for guidance and coordination of all agricultural research activities in Uganda. NARO is a Public Institution established by an Act of Parliament (The NARO, Act 2005). Among its functions are to;

"Provide strategic direction for publicly funded agricultural research in Uganda and act as a forum for agricultural researchers in Uganda; Coordinate and oversee, in collaboration with the Uganda National Council for Science and Technology and other lead agencies, the development, consolidation and implementation of agricultural research policy and national research strategies, Set national priorities and harmonize agricultural research activities of the national agricultural research system, constituent institutions and public agricultural research institutes, civil society organisation, private sectors and farmer organizations and promote delivery of quality and efficient agricultural research services"

In fulfilling of its mandate NARO manages seven specialized Research Institutes and nine zonal Agriculture research and Development institutions across Uganda. In addition NARO works in collaboration with Makerere University's College of Agriculture and its field work stations and other interested International Agencies. NARO also undertakes collaborative Research in different aspects of sustainable agriculture, agriculture systems and food security.

However, it is under the Banana research cluster that an aspect of research data management was introduced with the purpose of increasing research data re-use. Further examination of the concept showed that their approach was creation of a data base for all research data sets generated from the different field undertakings of the cluster. Their approach is an effort in the right direction but leaves much to be desired regarding Research Data Management.

3.2 Medical and Health Research

Medical and health research was pioneered by the Uganda Virus Research Institute established in 1936 by the International division of the Rockefeller Foundation as a Yellow Fever Research Institute. In 1950 the Institute became the East African Virus Research Institute under the East African Community. The same year it was designated as WHO Regional Center for Arboviruses Reference and Research. In 1977 the East African Community collapsed and the Institute was subsequently named the Uganda Virus Research Institute. After the discovery of the Human Immunodeficiency Virus (HIV) in Uganda, research work with collaborators on HIV started in 1987. In 2009, UVRI became a constituent institute of the Uganda National Health Research Organization (UNHRO), an umbrella organization for health research within Uganda. The UVRI engages in health research pertaining to human infections and disease processes associated with or linked to viral aetiology and provides expert advice, enables partnerships and communication and serves as a center for training and education. UVRI conducts public health related research. The Institute's programmatic activities currently comprise of: Basic research; applied research (intervention, diagnostics, clinical, operational); Social/economic research; Capacity building through infrastructure and human resource development; Advice for regulation, policy development and quality improvement and Innovations.

In addition, Makerere University College of Health Sciences and Joint Clinic Research Centre (JCRC) among others have conducted several research studies; scientific and social researches that have shaped policy and guidelines in Vaccine development, HIV care, PMTCT, Treatment, Pediatrics in Uganda and the World over. These have been instrumental in building research capacities in the medical and health sciences fields, especially in HIV/AIDS, malaria and tuberculosis research. Unfortunately, the current research policies are not effective in handling the research data management aspects of their research works.

Makerere School of Public Health is one of the four schools under the College of Health science. Apart from training, it undertakes high quality research in different aspects of public health. The school has four departments namely; Department of Health Policy, Planning and Management, Department of Disease Control and Environmental Health, Department of Epidemiology and Biostatistics and Department of Community Health and Behavioural Sciences. It also houses the Regional Centre for Quality of Health Care. The standard research policy is silent about research data management and research data re-use.

Infectious Disease Institute (IDI) is not-for-profit organization whose Mission is to strengthen health systems in Africa, with a strong emphasis on infectious diseases, through research and capacity development. Established within Makerere University, the Institute began in 2002 and currently provides care and treatment services to over 110,000 people living with HIV in urban and rural settings in Uganda (directly through medical clinic, and in partnership with government and non-government health facilities) which amounts to about 13% of the national effort. IDI also provides extensive prevention services (including medical male circumcision) and is a national referral centre for complicated cases of HIV. Individual research works have their research protocols some of which have aspects of RDM that favors Research Collaborators due to the funding requirement from their countries of origin other than the host nation. When it comes to implementing the same, the Uganda research policy guidelines are implemented which lack aspects of RDM and research data re-use.

Makerere University and University of California, San Francisco (MU-UCSF) Research collaboration; the mission of the MU-UCSF Research Collaboration is to 1) conduct high-quality research in infectious diseases and strengthen infrastructure to help integrate research into policy by linking researchers and policy makers. In 1998, the MU-UCSF Research Collaboration focused on characterizing the efficacy of new antimalarial therapies, defining new public health approaches to malaria and understanding the evolution of antimalarial drug resistance in urban and rural Ugandan settings. In 2004, MU and UCSF investigators began studying other infectious diseases including HIV and TB. Each individual research work has its own protocol to follow, however, much of these protocols are silent about research data management and data re-use

Baylor-Uganda in response to the increasing demand for coordination of research activities in the organization, opened a Research Unit in 2007 and recruited an epidemiologist to head it. Over a period of 5 years, significant progress has been realized including the development of systems for research such as a Research Policy for the organization and a Research Agenda that focuses on topics of relevance to the organization. However, the policy is also silent about the needs of RDM and research data re-use

Overall in Health and medical related research the research policy guidelines provide for availing research data for only five years after the research has been completed and permanently disposed of thereafter. In Collaborative research, International agencies and Western world Universities, research data copies are submitted and kept within Research Data Repositories in their respective countries as a requirement from their funding agencies. This have long term effects to the research data sources as after the stipulated time frame that data is lost in host institution but remains active and available to third parties many years after the initial research. Such research data can then be re-used resulting into new meaning and consequently new findings which gives value to RDM and its accruing benefits.

3.3 Industrial, Engineering and Technological Research

Uganda Industrial Research Institute (UIRI) is a centre of excellence for the East African Community (EAC) in industrial research. The institution has evolved into a competence and capability centre which champions innovations, translates applied research results into practical applications; that include products and industrial processes, imparts technical skills and deploys technology across Uganda. However, the research policy and guidelines are silent about research data management and research data re-use.

Uganda Institute of Information and Communications Technology (UICT) established in 1965 as the East African Posts and Telecommunications Training Centre. The Institute offers training in all fields related to the communications sector; including Telecommunications Engineering, Computer Engineering, Information Technology; and Business and Management studies. Its mission is to provide high quality market-driven and sustainable training, research and consultancy services that support the ICT sector.

Overall, in Industrial, Engineering and Technological Research no information is available regarding Research Data Management and research data re-use although, research ethics are highly emphasized.

3.4 Social Science and Humanity Research

A number of research institutions are currently engaged in social science and humanity research. Among which are;

Makerere Institute of Social Research (MISR) has had a proud existence since its establishment in 1948. Today, MISR takes a critical look at how it has been shaped by this legacy, in particular the impact of 'market forces' over the past decade. In the face of a growing and pervasive culture of consultancy, MISR is committed to its original vocation, social research. Although, it is known for producing high quality research work, its research policy and guidelines are silent about research data management. It seems there is even no effort towards its adoption and inclusion into the Research policy

The Center for Basic Research (CBR) was established in 1988 as an educational trust, and then registered in 1990 as a Non-Government Organization. CBR focuses on research of basic social significance including; history, political economy, sociology, political science, law, education, and the sciences. Apart from accumulating diverse reports and their inclusion into their Library, there is no repository for research data and lacks any informed research data management plans.

Based at Makerere University, the Economic Policy Research Centre (EPRC) is Uganda's leading think tank in economics and development policy oriented research and policy analysis. It was established in 1993 as an autonomous not-for-profit organization limited by guarantee to fill fundamental voids in economics research, policy analysis, and capacity building for effective in-country contributions to Uganda's policy processes. Today EPRC is a reputable, credible and independent policy think tank in Uganda renowned for providing research based evidence and policy analysis to support the formulation, implementation, monitoring and evaluation of government policies. Research areas include; Agriculture; Economic development; Education & Health; Employment; Governance; Natural Resources; Policy; Poverty; Private Sector and Trade.

Overall, the leading institutions in Social Science and Humanity Research policy and research guidelines apart from emphasizing the ethics in research and quality control, they are silent about research data management. They have no research data repository and therefore lack the infrastructure requirement for RDM and possible research data re-use.

4. Legal and ethical issues in research data re-use

The existing legal framework show that, there has been a slow response with regard to Research Data Management. The National Guidelines for Research involving Humans as Research Participants of 2014 in the section on responsibilities of researcher, sponsor and Researcher's organization of affiliation states that it is the researcher's responsibility to;

ensure good documentation of all study procedures and data; i) Put in place a quality assurance system for proper conduct of the study in order to preserve integrity of the data; m) Take, together with his/her research team, a recognized research ethics course or equivalent within three years prior to commencement of the study; and thereafter, have a refresher course at least once every three years. Student supervisors at training organizations are similarly encouraged to take basic research ethics courses.

From the above policy statement, emphasis is more on research ethics rather than the research data and its management. About the possible re-use of the research data; it states that

"The consent form, which is separate from the one used for enrollment of research participants into the study, shall include the following components: purpose of sample storage, quantities of samples to be stored, place where samples will be stored, measures to protect confidentiality, policies that will govern use of the samples in future research, potential risks and benefits of storing samples for future research and any other information deemed necessary by the researcher or REC. The research participant shall be given the option to choose whether his/her sample should or should not be stored for future studies. A Ugandan scientist shall be included as co-investigator in all future studies using the human materials collected from Uganda any future research study on such samples is subject to review by a REC"

About the ownership of the Research data, the policy states that

"Sample sources own the samples. Samples sources may withdraw their samples if the samples are linked. Samples shall be held in trust on behalf of the sample sources by a duly registered and recognized organization in Uganda. The organization entrusted with custodianship of the samples shall have the authority to decide use, transfer, storage and future use of the samples taking into consideration rights and welfare of the research participants".

The policy has a clause that refuses indefinite storage of research data particularly if it relates with human materials.

"A date for termination of use of the material may be set to avoid indefinite use of the material by the recipient organization. This date may be extended by written mutual consent of the parties. At the termination date, the provider organization may ask for the return of the material or its destruction. It should be noted that terminating use of the material does not render null and void other provisions of the Material Transfer Agreement (MTA). It should be mentioned if the material would be stored for future unknown uses"

The legal and ethical issues in Research data management relate with; Intellectual property rights defining the relationship between data ownership and usage of that data. Copyright protection of data owners from others producing unauthorized copies of their work, distributing copies of the work, or producing derivative works from the original. Consequently, when reusing data researchers must clarify the restrictions as to what can and cannot be done with data. Licenses and conditions of use provide for where data are published with specific licenses and conditions that define the rights of usage.

Codes of ethics govern all research and are applied as guidelines of; non-malfeasance embracing informed consent, anonymity, and confidentiality. These are intend to protect participants from any potential harm caused by participating in research. The critical one among them is anonymization which applies to two kinds of identifiers: direct and indirect. Direct identifiers are the obvious variables like; name, address, or telephone numbers that specifically highlight a participant. Indirect identifiers when pieced together could also reveal an individual including; cross-referencing occupation, employer, and location. Confidentiality is making your data available for reuse and does not entail uncontrolled, unrestricted public reuse. Most institutions are advocating for "open data" - available without restriction - provided it does not contravene consent and anonymity commitments. However, the focus in social sciences on human subjects often means safeguards on access have to be in place.

In Uganda, UNHRO policy requires an establishment of a Data and Safety Monitoring Board (DSMB) for each medical research undertaking. It is composed of independent group of experts established by study sponsors to review the data safety during clinical trials. It is to ensure that a study is conducted and data are handled in accordance with provisions of the research protocol. The DSMB also monitors adverse events and safety data.

Institutional Biosafety Committees (IBCs) are established by organizations that undertake research on potentially hazardous substances of a physical, chemical, biological, or any other nature. Any organization involved in or planning to conduct research with potentially hazardous substances is required to set up or designate a competent IBC. Unfortunately, Uganda has not yet moved with the trends and therefore has no legal basis for enforcing Research Data management and consequently Research data re-use.

4.1 Capacity Development in RDM

LIS Education and Training institutions have sprung up in several universities in Uganda offering LIS programmes (Kigongo-Bukenya and Okello-Obura, 2011). Available curricula, show that many curricula are replicated in many aspect without reflecting the unique needs of the country and the global professional trends. Although, some curricula have incorporated aspects of Information Communication and Technology, they are quiet about Research data management at any academic certification level available. This is further indicative of the lack of the human resources across the country with relevant skills and knowledge in the field.

5 Strategies for Research Data Management in Uganda

Historically, libraries have served as institutions where information is collected, curated, preserved, described, discovered, and accessed. Putting these traditional library activities into data terms illustrates why academic libraries and librarians should be involved in the management of scholarly information and research data.

Libraries in Uganda, should recognize research data as a scholarly asset that should be stored and made available for reuse, just as any publication is. This is particularly important as data has become more widely accessible in its digital form and its use for experimental validation and reuse in extending the boundaries of knowledge has become more practical.

Developing the capacity of Librarians in Research data management should be taken as a strategic choice for all research Institutions. This therefore requires developing and designing appropriate RDM curricular suitable for different levels of Library professions.

Short courses for already practicing librarians with interest in RDM should help institutions to spearhead introduction of RDM as a service within their different Libraries. In addition, there should be a short course in RDM for Students pursuing; Masters, PhD and Postal PhD studies.

An effort should be made towards developing an Institutional Repository for Research data sets from all researchers in academic fields. This can be spearheaded by Makerere University Library since it already has the pre-requisite infrastructure for the purpose. The UNCST should work toward establishing an Institutional Repository for research data sets for different collaborative research work in Uganda for its effective protection and availability for future usage.

The UNCST should introduce aspects of RDM plans in all its research policy document and guidelines as mandatory for all research work undertaken in Uganda

This is work in progress, and there is urgent need to undertake an in-depth study of the subject to fully understand, the evolution of RDM and its manifestation across institutions in Uganda. This is anticipated to form a basis for establishing a strategy for adoption and integration of RDM and Research data Re-use in research works across different Higher Education institutions in Uganda.

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