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Using the African Digital Health Library for cancer control: Dissemination of African cancer research output

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Access to published literature on cancer in Africa is problematic – especially locally produced cancer research information. A digital health library, such as the one being implemented in five African countries provides a solution. A new innovation, the African Digital Health Library draws support from local stakeholders, enlisting the best ideas from both the library and information technology fields. Although this work seems like new territory, it essentially remains a librarian’s workspace, supported by local collaborators and with new ideas to enable efficient access to cancer research information.

Evidence for cancer control principally comes from two sources: population-based cancer registries providing epidemiological data on cancer incidence, mortality and survival, and reports of research (basic, translational, clinical and economic) conducted in academic, clinical or commercial settings. In sub-Saharan Africa access to the former is improving with the support of the African Cancer Registry Network, but the latter remains problematic, with the lack of digitization making external access to valuable academic research particularly difficult. One project across five countries is trying to fill this gap by increasing access to locally published literature on cancer and by ensuring that it will be hosted in institutional repositories and made accessible globally.

Digital repositories are a recent phenomenon in African countries, and especially in universities. The traditional role of

a digital repository at a university in the United States is that of a storage place for faculty publications. These repositories are not usually accessible or user friendly as they are primarily used as warehouses of publications (1). Most African universities have embarked on establishing digital repositories with the objective of making their local content visible and permanently accessible to their users. They are an “increasingly significant component in the provision of academic publications and information resources” (2). These repositories are no longer just for storage, but are dynamic online spaces that clients may use for various purposes such as advocacy and marketing, ranking and as a general permanent archive. The digital health repositories in the five project countries of Mali, Kenya, Nigeria, Zambia and Zimbabwe were envisioned to be open, active and freely accessible to anyone with an internet connection.

The digital health repositories serve as vehicles for making African research, archival journal articles, dissertations and theses, as well as ministry of health reports, available to a global audience. For example, if African local research had been digitally accessible, responders and policy makers dealing with the 2014 Ebola outbreak in the three West African countries of Guinea, Liberia and Sierra Leone might have benefitted from being able to access reports from Uganda's outbreak in 2000 (1). It is common knowledge that a great deal of research has been carried out in Africa, by African academics. A substantial part of this research has been published as articles in international, regional and national peer-reviewed journals, while other research such as theses and dissertations are unpublished. Unfortunately, most of the published literature is not readily accessible by the institutions that produce it. The unpublished literature, such as dissertations and theses, are not accessible to a wider audience as they exist predominantly in print. Most of this research ends up on library shelves, where it is neither used to inform policy nor to generate further research. Although international funding has increased dramatically for biomedical scientists in Africa, there is little or no international access to the bulk of research that has been and is being carried out in the continent by African researchers. Importantly, this valuable information is generally not available to African researchers or their colleagues in the international community of global health and therefore does not inform current or future prevention, treatment, research and policy.

One of the ways of addressing this problem is to create Digital Institutional Repositories (DIRs). DIRs provide access to institutional research output by archiving it. They create global visibility for an institution's scholarly research and collect content in a single location, as well as storing and preserving other institutional digital assets, including unpublished (grey) or otherwise valuable information that could easily be lost.

A concerted action by a high-level network of African librarians in five countries has aimed to change that paradigm by creating institutional repositories that are searchable by anyone from any location worldwide. These DIRs aim facilitate

the dissemination of research output produced locally in the member countries of the Network of African Medical Librarians (NAML) as well as to the rest of the world. The ADHL project is implemented by NAML. It is locally led by medical librarians who, with the guidance of the principal investigators, have been collaborating and planning the project for several years. The Network comprises medical librarians from academic institutions in Kenya (Kenya Methodist University and University of Nairobi), Mali (Bamako University of Science and Technology), Nigeria (University of Ibadan), Zambia (University of Zambia) and Zimbabwe (University of Zimbabwe).

Country case studies

Accessing local cancer information in the five countries has been problematic. However, the ADHL project might be a solution to providing local cancer research to a wider audience; notably, facilitating access to this information by healthcare providers. The following case studies illustrate that within the short period that these repositories have been in existence, there is already cancer research that healthcare providers can reference in the delivery of healthcare.

Mali

Searching for "tumour" or "cancer" in the Mali Digital Health Repository database retrieves about 400 theses. The earliest documents related to liver cancer and stomach cancer surgery date back to 1981. These works that present the Malian context are not available in the published literature anywhere in the world. The digital copies have two origins: documents collected in electronic format from students (since 2002) and the documents digitized from hard copies the library had been collecting. The faculty has mandated the deposit of electronic copies. The older documents are being digitized when resources are available.

Zambia

The African Digital Health Library at the University of Zambia (3) has 232 items (of which 47 are cancer related) added from

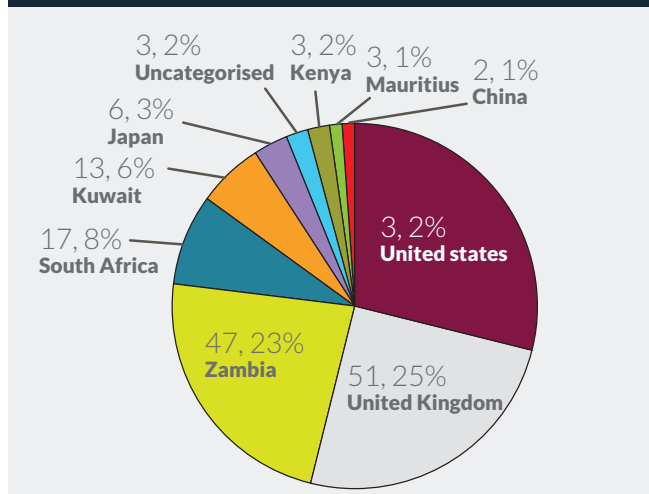
April 2018 to January 2019, and their combined full text downloads totalling 3,086 across all publications dates are shown in Table 1.

In terms of web traffic, we have seen the majority of access coming from the United States (59, 29%), United Kingdom (51, 25%), Zambia (47, 23%), South Africa (17, 8%), Kuwait (13, 6%), Japan (6, 3%), Kenya (3, 2%), Mauritius (3, 1%) and China (2, 1%). Three (2%) were not categorized. See Figure 1. There is also interest in the

Table 1: Breakdown by date of publication at UNZA ADHL

Publication date range	Total number of items	Total downloads	Average downloads
2010 - 2018	120	2,235	18.62
2000 - 2009	20	120	6
1980 - 1989	42	315	7.5
1970 - 1979	35	287	8.2
1967 - 1969	15	129	8.6
TOTALS	232	3,086	13.30

Figure 1: Views of research from the University of Zambia stored in the African Digital Health Library



content from within the country itself and from neighbouring countries, a phenomenon that can be observed from a digitization project of some African content (4) through a Department for International Development (DFID) funded Global Open Knowledge Hub project at the Institute of Development Studies in the United Kingdom (5).

However, as important as access to this African material is, the main outcome of this project was mentoring a group of seven librarians in five countries, their staff, their faculties, their information technology (IT) colleagues, and those they met with as they created the university-wide ecosystems required to hold the health repositories. The project output was working nascent repositories at each of the institutions, systems in place to support them, and training people to ensure their continuation. Repositories require systems and trained staff to support the entire process – from the scanning of the document to be deposited to the entry of documents into a database. Effective utilization of what is available requires people to make sure that the public are aware of the repository through training, marketing and advocacy. Consequently, vice-chancellors, provosts/deans, faculties, students, IT personnel and library staff are essential to this process.

Network of African Medical Librarians

NAML is an ongoing collaboration that has been working together since 2009 and comprises former United States National Library of Medicine Associate Fellows from Africa and affiliate librarians. The vision of NAML is to strengthen health sciences education, research and outreach for better health outcomes in Africa. The mission is to expand the frontiers of knowledge through training and outreach to African librarians, the academic community, healthcare professionals and health policy makers to source, organize and make use of this health information.

As a network, NAML has made significant advances, including the development of a training manual: *Finding, Organising, and Using Health Information*. The manual is available for free on the web at <https://library.adhl.africa/handle/123456789/2145> and has been used for conducting workshops for healthcare professionals at African universities and in outreach campaigns in the country. NAML has been active in improving access to research and healthcare information for researchers, students, healthcare workers and policy makers in Africa. The Network has also been involved in training students, health workers, academics/researchers and policy makers in member countries on accessing, retrieving and using online health information.

Funding for the project

The project is funded by the Office of the Global AIDS Coordinator (OGAC), the US Department of State, US National Library of Medicine and National Institutes of Health, and is managed by the US Civilian Research and Development Foundation (CRDF). The US National Library of Medicine has provided funding for high-grade scanners for the sites which did not have them. These scanners were purchased locally at each university.

Technology

The librarians collectively agreed on the Dspace software as the platform that was to be deployed across all repositories. This decision was partly based on the fact some of the countries were already using the software. Additionally, because Dspace is widely used on the African continent, availability of lessons from other Dspace users was much easier. There was also an agreement on metadata (data about data), which describe the content that was to be adopted. Dspace, an open source software, is a turnkey repository application used by many organizations and institutions around the world to provide access to digital resources. The librarians, working together as the NAML, identified the ecosystem that needs to be in place at each institution to support the Digital Health Repository (DHR).

Major activities for the IRs

Among the major activities undertaken were:

- ➔ Developing metadata standards to be used by all the Network Libraries.
- ➔ Identifying the appropriate software.
- ➔ Identifying technical expertise.
- ➔ Setting up an advisory sub-committee composed of key players.
- ➔ Developing criteria for the identification of contents.
- ➔ Scanning/digitizing the printed information to populate the IRs.
- ➔ Developing a federated search engine (ability to search

across the Network IRs).

- ➔ Training the librarians (administrators of the IRs) on use of IRs.
- ➔ Conducting training and advocacy workshops on open access and online publishing for the academic community and for authors and researchers on how to input and retrieve research evidence,
- ➔ Importance of on-site visits and training in the provincial nursing schools under the Ministry of Health in Zambia. The Zambia node has already embarked on this very important move of teaching health professionals how to easily access the resource to save lives.
- ➔ Marketing of the IRs within the institutions, nationally and internationally, while mentoring young professionals in their use and application.
- ➔ It is hoped that the provincial health professionals will in return inform their colleagues in the remotest health centres why this resource is useful to them.

Mentoring younger professionals

Mentoring is essential to building a strong DHR and for the ADHL, and this took place at all levels. Initially, the first phase comprised site visits by the project's principal investigators (PIs) who are based in the United States. They met physically or through conference calls with the individual librarians at each site. Together, they were to ensure that the policy makers, faculty, students, library staff, IT personnel and local ministries of health were all engaged, identify any gaps, and give assistance where needed. However, this approach was abandoned in favour of conference calls due to difficulties in coordinating site visits. The objective for the first phase of mentorship of the project at site visits was a narrative, budget, and timeline for each institution, created by the librarians with the help of the PIs. The budget for each site was based on the needs of each institution to support and sustain the digital health repository. This budget and narrative was then sent to CRDF shortly after the conclusion of each visit. The objective was for the librarians to be strengthened so that they can carry on with their own repositories as well as reach out to, and mentor, those within the network whose repositories might have been more nascent.

Content for the ADHL

Only local research content and outputs from NAML member countries was considered for the repository. The content included the following:

- ➔ journal articles published in open access journals;
- ➔ pre-prints of journal articles that were published in restricted journals;
- ➔ theses and dissertations produced by the NAML member country institutions;
- ➔ grey literature – e.g., conference, seminar and workshop papers, operational manuals, speeches, public lectures;
- ➔ conference proceedings;
- ➔ ministry of health technical and research reports;
- ➔ books and book chapters;
- ➔ policy documents from institutions policy documents;
- ➔ archival materials.

Phase 1: Preparation and site visits

The project's first phase comprised site visits by the PIs – who had worked extensively with library systems at regional, national and international level for over 40 years. The PIs and librarians at each site reviewed in detail the various components of the DHR and determined where the strengths and challenges lay. The budget and budget narrative were created at the conclusion of each visit or conference call. In addition to actual equipment and costs of building institutional repositories, the meetings made it possible for on-site peer-to-peer mentoring as well as solid continuation of mentoring amongst the project stakeholders to ensure that skills are transferred and sustained. At the conclusion of each site visit or conference call, budgets and budget narratives were specifically agreed vis-à-vis the librarians' original work plans and the project components to be completed, challenges to be addressed, and the schedule for the release of funds. Prior to the visit or conference call, each librarian provided a completed survey to be used as a baseline.

Phase 2: Implementation of DHRs at five sites

The second phase was the actual building of the DHR that had been agreed to during the site visit, as well as through email and conference calls. Prior to commencement of scanning, a technical expert trained both library and IT staff on the Dspace software. The training addressed the various work flows and the tasks of each person and how to effectively and efficiently carry out tasks without difficulties.

The basic objectives of Phase 2 of the project were the following:

- ➔ Create solid systems for DHRs at each site – this is the ecosystem of people, policies and resources that had been identified during NAML workshops.
- ➔ Educate and engage the university community – from dean/provost to faculty and students as to the importance of the DHR and ensure that a policy is in place regarding archiving requirements.
- ➔ Train library staff, IT personnel, students and faculty members on their roles.
- ➔ Digitize a reasonable amount of archival material from the

university (theses, dissertations, medical journals, reports and publications) and material from the ministry of health (many of which may be in digital form but are not linked to any database for easy access). Current material may already be in digital form and not require scanning, but must be incorporated into DSpace to be made accessible to all.

- ➔ Use Google Scholar or another widely available mechanism to enable free, easy access to the contents of the repository.

Phase 3: Marketing and promotion

From the onset, the DHR planned on conducting advocacy workshops for open access and online publishing among the academic community as well as training researchers and authors to input and retrieve the research output themselves. It is important to market the IRs within institutions and nationally.

Phase 4 - Evaluation of the project

Creating the ADHL is an activity that is self-sustaining, because once the content has been uploaded and the stakeholders have been trained, the project could continue without further funding. The member libraries continuously identified new research and added it to the ADHL. The librarians also mentored fellow librarians and users, and did continuous training of new researchers and authors to ensure updates and continuity of the project. A post-evaluation of the project was carried out by a) designing and sending questionnaires for content submitters and users, and b) generating usage statistics to assess the impact of the ADHL within the member institutions and beyond. Feedback from the questionnaires and usage data are to inform future decisions regarding the progress of the project.

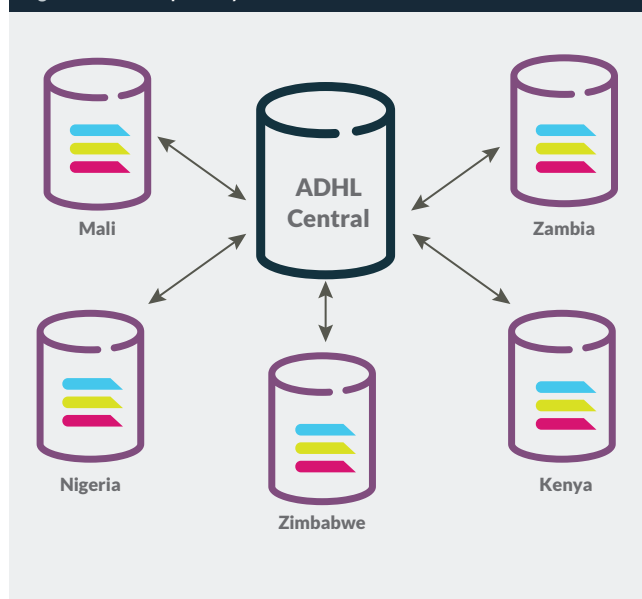
Phase 5 - Sustainability and expansion

- ➔ Mainstream the ADHL into the activities of the university libraries.
- ➔ Use more social media for ADHL promotion.
- ➔ Do an impact assessment and evaluate the collection usage in 2019.
- ➔ Make sure that ADHL becomes an essential service.
- ➔ Establish that each site embeds ADHL into their BAU (business as usual) operations.

Future ADHL architecture

The ADHL will enable access across multiple repositories, probably using a single view. The future for ADHL is one which is integrated, with Open Archives Initiative Protocol for Metadata Harvesting (OAI-PMH) and the Representational State Transfer (REST) based Application Programming Interface (API) that could be used for interoperability between

Figure 2: ADHL repository architecture



the various nodes (countries) and the central node (See Figure 2). Value-added services such as dashboards, Facebook, Google+, Instagram, Reddit, Tumblr, Twitter and YouTube could be incorporated at the central node.

Lessons learned

Several lessons that are critical to the development and success of the digital health repositories were learnt over the course of the project.

- ➔ The training of stakeholders is crucial for the successful implementation of ADHL.
- ➔ The need to work closely with ICT unit, faculty and administrators.
- ➔ Institutional capacity for Dspace and general digital repository principles.
- ➔ Continuous promotion and marketing of the DR to all stakeholders.
- ➔ Advocacy for adoption of Open Access policies by the institutions.

Conclusion

With the initial phases completed, the DHRs are on their way to becoming self-sustaining and the documents in the repositories are freely accessible and available on the Internet. The project has helped to create local partnerships between the medical schools and the ministries of health through the various hospitals across the countries who are the consumers of the information produced. The project has enabled cancer research information sharing among African biomedical researchers locally and regionally. Although project funding came to an end in 2019, the ADHL project will continue. ■

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Julia Royall has been working in international health in Africa since 1990 and has more than 40 years of professional experience in the communications field. As Chief of NLM's Office of International Programs, she created innovative programmes that focused on Africa. Now retired from US Government service, she currently serves as principal investigator for the African Digital Health Library (ADHL). She has lectured widely in the US, UK, and Europe, published in Medline-indexed journals, and been honoured for her contributions to global health.

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