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Establishing a Cancer Research Consortium in Low- and Middle-Income Countries: Challenges Faced and Lessons Learned

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Abstract

There is an increasing effort in the global public health community to strengthen research capacity in low- and middle-income countries, but there is no consensus on how best to approach such endeavors. Successful consortia that perform research on HIV/AIDS and other infectious diseases exist, but few papers have been published detailing the challenges faced and lessons learned in setting up and running a successful research consortium. Drawing on our experience of founding the African Research Group for Oncology (ARGO), we describe steps and key factors needed to establish a successful collaborative consortium between researchers from both high- and low-income countries. In addition, we present challenges we encountered in building our consortium, and how we managed those challenges. Although our research group is focused primarily on cancer, many of our lessons learned can be applied more widely in biomedical or public health research in low-income countries.

Introduction

Over the past 15 years, focus has begun to shift from high-income countries (HICs) implementing programs in low- and middle-income countries (LMICs) to the more collaborative approach of building capacity within LMICs.[1] In the realm of public health, this has translated into hospital training programs or large-scale project implementation.[2] In

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comparison, relatively little emphasis has been placed on collaborative research, or building research capacity within LMICs. This is beginning to change, and several papers characterizing principles for conducting research-strengthening activities in LMICs have been published.[3–8] Most research programs that have been implemented successfully in LMICs are focused on infectious disease research, which traditionally has been a high priority for the global community.

Several successful research consortia focus on HIV/AIDS. One example is AMPATH, a consortium between several Kenyan and 11 North American medical institutions. Initially, the aim of AMPATH was to develop health leadership in Kenya, but this collaboration quickly grew into a large-scale model for HIV/AIDS prevention and treatment.[9] They have now expanded to cancer research and training, including a formal gynecologic oncology fellowship program. Other research consortia have also been initiated on varying public health topics.[10–15]

In 2013, we established the African Research Group for Oncology (ARGO), our collaborative research consortium. This collaboration is between Obafemi Awolowo University (OAU), Federal Medical Center Owo (FMC Owo), University of Ilorin Teaching Hospital (UITH), Ladoke Akintola University Teaching Hospital (LAUTECH), Ondo Trauma and Surgery Centre, and University College Hospital Ibadan (UCH), all in Nigeria, St. James University in the UK, and Memorial Sloan Kettering Cancer Center (MSK) in the U.S. Our research consortium is unique since it focuses on cancer rather than infectious diseases and was founded by surgeons, who are generally the sole providers for all solid tumor oncology care in sub-Saharan Africa. In this paper, we describe the steps taken and components needed to establish a successful collaborative research consortium. We also present challenges we encountered in building our consortium, and how we managed them.

How to Begin - Identifying Collaborators and Common Research Questions

Building a robust and sustainable research collaboration requires identifying research partners. A good way to do this is by attending international conferences within LMICs. Other possibilities include interaction with regional specialty organizations. Specific to surgery, for example, one might seek collaboration through the West African College of Surgeons (WACS). If interested in cancer, one might attend the African Organization for Research and Training In Cancer (AORTIC) meeting. In identifying each other as partners, all parties should research each other's backgrounds, read previously published work, visit each other's institutions (where possible), and gauge institutional capacity based on laboratory and clinical resources.

Determining ARGO membership required careful consideration. Initial questions were whether the consortium should be throughout West Africa, across Nigeria, or only in southwest Nigeria. We decided to start small, including a group of hospitals in southwest Nigeria with personnel that had trained together or collaborated previously. ARGO has already moved from three Nigerian centers to five. In two more years, the consortium will expand outside of southwest Nigeria to include other Nigerian academic centers. The goal is to eventually have regional members throughout West Africa.

Another key for sustainable partnership is shared research interests. ARGO was created after one of the authors (OIA) from Nigeria completed a Soudavar fellowship at MSK. Post-fellowship, reciprocal visits to the medical centers revealed common research interests and clinical questions. When selecting the cancers we would study initially, we felt it important for the cancers to be common, have outcomes requiring improvement, and be treatable by surgeons, as this comprises the core of ARGO. Given the high volume of colorectal cancer (CRC) patients and dearth of data on the etiology, outcomes, and optimal therapies for these patients in Nigeria, we decided to focus on CRC. Breast cancer is much more common and also has poor outcomes, but ARGO members saw that there are already teams working on breast cancer research in sub-Saharan Africa, so CRC was a unique starting point. When founding ARGO, we planned to build infrastructure that could be applicable to any cancer, allowing ARGO, after two years, to expand the consortium to other common cancers (such as breast and cervical).

For our initial research question, we decided to determine prospectively who gets CRC, their presentation and recurrence patterns, and their outcomes. These data are a required baseline before any screening or therapeutic trials can be developed. The principles that were used to choose this question were: 1) Is the question clinically relevant? and 2) Can the question be reliably answered with our infrastructure in a timely fashion?

Forming Your Research Team

Once collaborators have determined that their research interests are synergistic, there must be a catalyst for building the consortium. In our group we began with retrospective studies, as this provided a quick snapshot both of research capacity and cancer outcomes. This allowed us to understand partners' limitations and assess realistically what each side of the consortium could offer in terms of time, resources, skills, and knowledge. We found it best to balance the team composition with a mixture of more junior —but highly motivated— personnel and more senior members to act as advisors. Involvement of physician members of the diaspora shapes the consortium with accomplished physicians who also understand the culture of medicine in LMICs.

To start a collaborative research consortium, financial support must be available for at least three years. This time period allows for analysis of current cancer needs and patient outcomes, completion of several retrospective research projects, generation of prospective research project ideas, and application for funding opportunities. A similar timeframe can help other consortia to conduct exploratory analyses to identify research that is relevant to the local setting. In addition, metrics for success in the first year can be generated collaboratively and subsequent years can be used to assess and meet these metrics. The first person we hired was a research coordinator with a college degree in medical recordkeeping. This was important because it allowed us to spend most of our time on research and not administration.

It is important to ensure that you slowly and strategically build a staff capable of executing research goals. We found it particularly important to employ a research team whose members are able to work independently. In addition, it is important to show the same

consideration for LMIC physician-scientists as for HIC physician-scientists in terms of effort on each research project, thereby providing financially-supported research time. It may not be practical for a LMIC physician to have protected time due to physician shortages, but assigning a percentage of effort at least provides financial remuneration for research endeavors.

Building Infrastructure

Infrastructure solidifies your research consortium, especially in an international context between HICs and LMICs. Training is important in global collaboration, especially since there is still a gap in knowledge and skills between HICs and LMICs in many aspects of clinical and biomedical research.[16,17] ARGO is now using the Cornell Master's in Clinical Research program to bolster the skills of health workers within the consortium, and pathologists or pathology technicians from OAU will visit MSK and St. James to learn methods to improve their pathology processing and interpretation. In Nigeria, a country with fewer than 200 practicing pathologists for a total population of over 160 million, it would take generations to educate enough pathologists to meet the needs of all of their patients. By utilizing web-based evaluations from HICs, this process can be expedited, and the HIC is taking some responsibility for LMIC improvement in clinical and research practices.

There is no single model to overcome the massive need for pathology services in LMICs. The most successful efforts have used a combination of in-country training, improvements in pathology techniques, and remote assistance.[18] This is one area that is ripe for technological innovation, as demonstrated by the NCI's UG3/UH3 cancer diagnostics academic/industry partnership grant mechanism. The disparity is so large that an entirely new pathology platform is likely to be required for significant progress.[18]

In addition to clinical research training, emphasis should be placed on training LMIC staff to provide research management and administration, grant-writing support, and other non-medical, administrative activities. ARGO has managed these challenges in several ways. First, when the US-based clinicians are not in Nigeria, there are weekly calls between the groups to update staff on any issues (e.g., database management). In this model, both sides are engaged not only in the clinical research, but also the non-scientific aspects of the consortium. For example, a robust Quality Assurance (QA) program was initiated with research staff at MSK to assist with remote database QA.

It is also important to include training in medical and research ethics, protection of human subjects, and protocol development. Many foreign institutions or countries have their own ethical review boards, but the consortium should harmonize and strengthen protections across partners. Available resources differ depending upon the setting, but employing various health information systems (e.g., a cancer registry or secure database for patient samples) is important for protection of patient privacy in any environment. One caveat is to avoid being too "high-tech" at the beginning. Once personnel are properly trained and laboratories have made the appropriate accommodations, you can begin to introduce better technology. Doing so too soon can be a waste of money and a point of discouragement for the entire group. For ARGO, we initially used the data management system that was already

set up at MSK. After 3 years of using a custom database, ARGO expanded to REDCap (Research Electronic Data Capture) in 2016 to improve and expand our current data management capabilities.[19]

Another major challenge exists with respect to laboratory and clinical equipment, due to the infrastructural gap between HICs and LMICs. It is important to identify the necessary equipment and acquire each piece gradually as resources become available. One approach is to build equipment costs into grant proposals. Some LMICs find innovative ways to adapt older equipment to the research environment,[12] but we caution against using substandard equipment, which can save on initial costs but may affect the validity of research results. In addition to the equipment itself, electricity can be an issue due to frequent power outages in some locations. In our case, we use both backup power from the hospital's generators and an inverter system to maintain a constant supply of electricity to our lab.

In situations where necessary equipment or training is lacking, it makes sense to ship samples back to the HIC partner for processing while local infrastructure is still being developed. In our group, we attempted multiple shipping options. We have shipped both fresh, frozen tissue in liquid nitrogen, and tissue in paraffin blocks. The quality and amount of DNA from the fresh frozen tissue is much better than those from the paraffin blocks, however, it is paramount to find a trustworthy shipping organization. One large commercial shipping organization allowed our frozen material to sit at customs for longer than was acceptable, so we lost the entire shipment of tissue.

Funding Your Research Consortium

Research funding is an important topic in both HICs and LMICs. There are many more financial constraints in LMICs than HICs, but this does not mean that robust results cannot be produced within LMIC budgets. For example, in one study conducted by ARGO, colonoscopies for 100 subjects cost less than $15,000, whereas in the U.S. a similar study would cost up to $200,000. Foreign funding for conducting research in LMICs is sparse,[20] so having a HIC partner could help garner important resources for the consortium. ARGO received a pilot grant from the NCI's Center for Global Health to initiate its database and biobank. Additional options that ARGO has found for funding include the Fogarty International Center (K43 award for LMIC investigators) NCI (P20 Regional Center of Research Excellence, UG3/UH3 Cancer Diagnostics for LMIC, R21 Trauma and NCDs in LMIC), Wellcome Trust, AORTIC BIG CAT grant, UICC ICRETT grants, MSK global cancer disparity pilot grants, and private foundations.

Publishing Within Your Consortium

For research collaborations, publication is important to discuss at formation. Authorship determinations can trigger conflict in any collaborative setting, and members of each team should make an effort to acknowledge each researcher's contributions to the study process and final product. It is not good practice for the HIC researcher(s) to always be listed as first and/or senior author. Such an imbalance in the partnership detracts from its sustainability.

Expanding Your Consortium

Expansion is important to get enough variability in the study subjects and sufficient statistical power for the results to be meaningful, but if it happens too quickly, expansion will stretch resources too thin and projects will likely fail. We started with a focused question, a finite number of patients, one research employee, and four centers. As our infrastructure developed, we expanded to six centers and three full-time, paid research staff. This has all happened gradually in a consciously step-wise approach, with consideration given to implications for the research team, laboratory, and QA.

Another aspect of expanding our consortium is inclusion of more non-surgeons. In most LMICs surgeons are the sole providers of cancer care, providing all services that medical oncologists provide in HICs. This is why in Nigeria, the core members of ARGO are surgeons, pathologists, and radiologists. In countries where medical and radiation oncologists are more common it is vital to include them in any cancer consortium, either initially, or when expanded beyond surgery. Finally, cultivating innovation will allow for exciting advances that can be introduced and tested with new partners.

Research Relationship Maintenance

Once your consortium is functioning, a good amount of management and process-driven work is still needed. Ensuring that everyone remains focused on similar goals, that research interests are constantly renewed, and that the work being done is novel, innovative, and important are all necessary to keep the consortium operating smoothly. It is advisable to designate milestones for staff with identified mechanisms for improving career satisfaction (e.g., with grants, recognition, speaking engagements, publications, etc.). In addition, it is wise to leverage research infrastructure from existing communicable disease consortia so as not to waste time building processes that already exist.

To ensure that success is achievable, goals and expectations of the consortium members must be realistic. ARGO decided to include metrics that evaluate both research and training efforts. Our research metrics were to publish two retrospective cancer manuscripts in the first 3 years, generate a prospective clinical trial that could begin enrolling patients within 3 years, and submit one successful NIH grant application. The training metrics were to identify and initiate formal postgraduate training in cancer research for ARGO members, and initiate pathology infrastructure building, specifically with immunohistochemistry training with pre- and post-training QA. At every annual ARGO meeting the metrics are revisited and an expanded set is proposed to adjust for continued growth.

Another important component of research relationship maintenance is obtaining support from the leadership of the HIC institution. This can be challenging given that research money is increasingly limited and it can be difficult to arrange for time away from the institution when clinical responsibilities are put on hold. In addition, a common question is why efforts should focus on global oncology when there are disparities in cancer care and outcomes locally and regionally in the US. In order to overcome these barriers the importance of global oncology should be demonstrated, using the multiple NIH funding

mechanisms that now exist and the recent Lancet Oncology Commission on global cancer surgery[21] as examples of the global oncology community's commitment to this area. In addition, institutions should realize that knowledge gained from working in LMICs and the publicity focused on the altruistic side of this work can be helpful for institutional growth.

In HICs, the great demand that decides the success or failure of research is time, as resources are important but rarely the limiting factor. In LMICs, the time demands can be even greater given the clinical load and understaffing, but resources are equally critical and must be considered in any plans. As the need for cancer care in LMICs continues to grow, the ability to create sustainable, innovative, collaborative research groups will become vital. Ensuring success will require continuous reflection on and sharing of successes and failures that occur in creating and sustaining research consortia in LMICs.

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Synopsis

Cancer is a growing public health problem in low- and middle-income countries. Multinational and multi-institutional studies are required to determine optimal diagnostic and treatment strategies for cancer in resource-limited environments. In this manuscript, the African Research Group for Oncology reports on lessons learned from establishing a cancer consortium in Africa.