MEDIATING FACTORS FOR BUILDING RESEARCH CAPACITY IN LOW-INCOME COUNTRIES: IMPLICATIONS FOR GLOBAL HEALTH RESEARCH PARTNERSHIPS

by

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ABSTRACT

Global health research takes place within the North-South divide and is commonly led by Northern investigators who come from resource-rich research environment, while Southern partners join the partnership with a paucity of these skills and resources. The asymmetry within North-South research partnerships merits careful attention to optimize the research process and application of the research results. This study uses a validated research tool entitled "Is Research Working for You?" to facilitate a qualitative investigation surrounding the benefits and challenges to engage in the research process experienced by The AIDS Support Organization (TASO), a Ugandan HIV/AIDS organization. Qualitative results document TASO's ambition to develop a Southern-initiated research agenda and the strategies they use to sustainably build institutional research capacity.

Keywords: Capacity building; Research partnerships; Neo-colonialism; Sustainability; Uganda

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TABLE OF CONTENTS

INTRODUCTION

The North-South divide is the geopolitical and economic rift that exists between the resource-rich countries collectively referred to as the "North" and the resource-limited countries collectively referred to as the "South" (1-3). Global health research typically takes place within the North-South divide and is most commonly led by Northern researchers in partnership with Southern organizations (4, 5). A common challenge for North-South research partnerships occurs because they operate within a historical legacy where the Northern partner is highly trained in research methods and comes from a resource-rich research environment, while the Southern partner joins the partnership with a paucity of these skills and resources (6). The asymmetry within North-South research partnerships merits careful attention to optimize the research process and the research outcomes for all partners. The local expertise and capacity of the Southern partner is an essential, and at times overlooked, component of the global research process.

North-South research relations have become prominent in global health research and as such there is a growing body of literature surrounding the challenges of conducting research in resource-limited settings within North-South research partnerships (4-10). Southern scholars have recognized that research as a tool is predominantly a product of the North developed with limited Southern collaboration (11, 12). This creates a dynamic where the Southern partner has

little input into the research process (e.g. research design, development of research tools, etc.) and remains quite dependent on Northern partners to conduct research. As a result, many North-South partnerships are criticized for remaining semi-colonial in nature, as the control and benefits of research (e.g. publications, results, research skills, etc.) continue to accrue to the North (8). Jentsch et al. draw on the metaphor of the unrecognized potential of 'Cinderella' to illustrate the continuing neocolonial attitudes to research which inhibit the development of mutually beneficial collaborations between the North and the South (9). 'Parachuting', where Northern researchers travel to the global South for a few months and take back clinical samples or research findings to be analyzed in the North is still a common global research practice. This practice is a result of the geographic North-South divide and is not inherently detrimental, however it does have the consequence of impeding the development of a suitable research infrastructure with authentic collaboration from the Southern partners (4, 5, 10).

Fully incorporating Southern partners into the research process presents an opportunity for Southern knowledge producing systems to be integrally linked into the global research agenda (5). This degree of Southern representation is a powerful mechanism to bridge the knowledge divide produced by the North-South divide. Best practices for equitable research partnerships recommend mutual trust and shared decision making between partners, national (i.e. Southern) ownership of data and findings, strengthening the connection between research into policy into practice (13), and the use of global research projects as

a vehicle to develop a national research capacity (4). Prioritizing these core principles in the global research process still remains a significant gap in practice and, as a result, limits the potential for research capacity building among Southern partners (5, 8, 10, 14).

Unfortunately, there are very few successful models of how to (re)negotiate the terms of a research relationship. One of the few comes from community-based participatory research (CBPR), which is designed to mitigate the challenges inherent in asymmetric research relationships (e.g. between academics and disenfranchised communities) (15). CBPR pays particular respect to community autonomy and strengthening the capacity of the community to use the results of research to improve control over their lives (15-17). Although CBPR is beginning to gain traction in the context of global health (18, 19), it is still relatively uncommon approach and much of the research conducted in Southern countries is not community-led.

Another example of renegotiated terms of reference has been documented among Aboriginal people where it has been commonly felt that research has been used as an instrument of oppression, imperialism and colonialism (12, 20-23). The Canadian First Nations Information Governance Committee developed the principles of Ownership, Control, Access and Possession (OCAP) specifically in response to the negative experiences with research and to gain control and rebuild trust in the research process (24). These principles protect all information concerning Aboriginal people, their traditional knowledge and culture and provide a way for Aboriginal Canadians to make

decisions regarding what research will be done and for what reason. There has been considerable progress made in the inclusion of Aboriginal people within the research process in North America, but this still remains a critical area for future development within the context of global health.

Meaningful Southern inclusion can increase social value within the research process and bring integrity and relevance to the research outcomes (13). The involvement of the Southern partners can strategically inform the development of a demand-led research agenda as projects develop in response to local needs (8, 25). Moreover, it has the potential to build community capacity to conduct and use research in a meaningful way (26). If Southern researchers participate fully in each phase of the research process, it will increase their ability to design and conduct a study, collect, analyze and interpret the results, and disseminate and ultimately use the findings to advocate for change (27).

Within global research partnerships the opportunities to build research capacity are often present but not always optimized. As a result, Southern partners continue to 'host' research led by Northern researchers and struggle to build the necessary capacity for Southern-led research. This illustrates the need to further investigate strategies to assist Southern countries to build local research capacity so that they can undertake studies in their own setting for their own purposes (26).

TASO Case Study

The AIDS Support Organization (TASO) is one of the oldest indigenous HIV organizations in Africa (28). It was founded in Uganda in 1987 by a group of people who were either living with, or deeply affected by HIV/AIDS in order to provide psychosocial support and basic medical care to individuals who were infected with HIV/AIDS. TASO works in partnership with many global health research institutes and hosts several innovative and complex research projects. In light of the proliferation of research activities, TASO management recently included research capacity building into its current five-year strategic plan (29) and created two main mechanisms to support research capacity - an institutional review board (IRB) and research committees located at each branch. Much research conducted at TASO goes through the Ugandan Virus Research Institute (UVRI) or the Ugandan National Committee for Science and Technology (UNCST) which serve as traditional ethics boards and ensures that research meets ethical standards for the protection of human subjects (30). In addition to this, the IRB at TASO is designed to ensure that TASO is fully engaged in the different stages of research process. The research committees are composed of TASO staff (e.g. nurses, doctors, counselors, data managers, field officers etc.) with previous research experience and are located at each branch as a strategy to decentralize research capacity building at the branch level.

Project Objective

The impetus for this research project emerged during the launch of the TASO IRB where members expressed a desire to have more control over the

"rules of engagement" during the research process with Northern partners. The primary author (K. Muldoon) presented the OCAP principles as an example of how the Aboriginal people in Canada reclaimed the research process to promote beneficial research and its ethical application in the Aboriginal context (31). A dialogue ensued which highlighted the need to evaluate how research was currently unfolding at the branch level from the perspectives of TASO staff members. This present study was initially designed to explore research capacity at TASO and a report was generated and circulated back to the TASO branches (discussed below). The objective of this paper is to present the benefits and challenges of engaging in the research process from a Southern partner's point of view and document the development of a Southern-led research agenda.

METHODOLOGY

Research Design and Data Collection

The research committee members from four of TASO's 11 branches were invited to participate in a qualitative investigation of research capacity at TASO. The selection intended to maximize regional representation, with the exception of the Northern region because of time and resource limitations. Both TASO-Mulago and TASO-Jinja are located in the Central Region, TASO-Mbale is located in the Eastern Region close to the border with Kenya, and TASO-Masaka is located in the Western Region. These particular branches were chosen from the each region because they have significant experience working in North-South research collaborations.

Descriptive data was collected using the scientifically validated tool 'Is Research Working for You? A self-assessment tool and discussion guide for health services management and policy organizations', developed by the Canadian Health Services Research Foundation (32). This tool is divided into four parts focusing on the acquisition, assessment, adaptation and application of research findings within a health organization setting. Each of the four parts contains five to fifteen questions using a five-point likert scale, where a one means the organization has low capacity in that area, and a five reflects high organizational capacity. It has been scientifically validated by Korthari et al. (2009) and demonstrates good usability and strong response variability, although

the discussion based on the tool is stressed as the highly useful aspect of the exercise rather than the scores themselves (33). The Alliance for Health Policy and Systems Research, a program affiliated with World Health Organization (WHO), has also used this tool in several global settings to enhance the application of research in health policy making (34).

A convenience sample of research committee members who were available and interested was sought at each of the four TASO branches. Nineteen research committee members completed the survey. Of the nineteen participants, twelve (six from TASO-Jinja and six from TASO-Mbale) were available to participate in in-depth interviews to explore their reactions to the survey and experiences with research at TASO. Because the survey was developed in a Canadian context, the in-depth interviews were left open-ended to allow respondents to focus on areas that were relevant to them in their cultural context and experience at TASO. All interviews were conducted by K. Muldoon in English and recorded. They lasted 40 to 60 minutes. This research was approved by the Research Ethics Boards of Simon Fraser University, the University of British Columbia, and the Ugandan Virus Research Institute, and was approved by TASO (see Appendix 1-4).

Data Coding and Analysis

Survey data were entered and analyzed using SAS 9.2 (35). Descriptive analyses were used to summarize the central tendency and dispersion of the survey responses. The in-depth interviews were transcribed from the recordings and double-checked for accuracy. Transcripts were entered into QSR NVivo 8

(36) to organize and analyze the qualitative data. Preliminary codes for the

qualitative data were co-developed between the first author and the TASO

research officer (J. Birungi) based on themes from the survey questionnaire and

interest areas at TASO. During qualitative coding, the codes were expanded

upon, additional coding was conducted to incorporate emergent themes.

RESULTS

Part 1: Descriptive Results

The descriptive results summarize the survey, which was comprised of 40 questions divided into four main sections (i.e. acquire, assess, adapt, apply) with one to two sub-themes in each section. There was a fair degree of homogeneity both within and between participants. Mean scores for each individual item ranged between 2.07 – 4.13 on a likert scale of 1 to 5. When the mean scores were ranked, internal communication and information exchange across the entire organization ranked high, as well as strong leadership from the management to prioritize research. Low ranked items included access to literature including peer-review journals, non-journal reports and websites. In addition, having enough staff with time, incentives and resources to use research and present the results to decision-makers and other staff also ranked low. Appendix 5 contains a summary of the descriptive statistics, ranked by item mean and section.

Part 2: Qualitative Results

Three key themes emerged from the content and thematic coding that described the research context at TASO. The first theme documents the reported benefits of research, the second theme documents the challenges the research committee members face in becoming more involved in the research process, and the third theme describes the institutional ambition at TASO to develop a Southern-led research agenda.

Benefits of Research

One of the dominant benefits described by the research committees was the ability for research to increase the credibility of the organization. Respondents valued the process of collecting data to inform their decision-making because, as one respondent explains, "… previously we've had no facts and it's very hard to base decisions on rumours or just estimations". They valued the process of research supported decision-making and appreciated how research had the ability to produce "an informed point of view", especially in the context of advocating for best practices for HIV/AIDS care. The respondents said that the Ministry of Health was now interested in the success of their HIV/AIDS prevention programming "…because we told them so out of the research that happened at TASO". Other respondents described a previously held generalization that seropositive people from rural areas would not be able to adhere to antiretroviral treatment (ART) for HIV/AIDS. Through a research project, TASO and its partners were able to prove that ART can be administered in rural communities with very limited resources through home-based AIDS care programming. These results were published in the peer-reviewed literature (37), and incorporated into the current standards of care delivery at TASO. As one respondent says, "Currently, with positives, we have many programs and many strategies that have come out of that study". The direct application of research to action was very encouraging for the research committees because it demonstrated the utility of research to affect change that benefited the clients. Using research to inform the decision-making both within TASO and at the National level was highly valued.

Beyond the national setting, several TASO staff attended international conferences to share research results on the global stage. Conferences were beneficial experiences and were described as a reward for the hard work of producing research findings. As one respondent describes, "… for people who put in the effort and the extra time it pays off because they get to go to conferences and in a way they get motivated." Not only were conferences appreciated as an opportunity to network with a critical mass of HIV researchers and broaden knowledge about HIV/AIDS, but respondents also voiced the importance for "the world to know what we are doing" in terms of innovative HIV programming and research. There was self-recognition that the work that TASO does is important not only for Ugandans living with HIV/AIDS but also as an example of a care centre located in a resource-limited setting and functioning effectively. Respondents described how international conferences gave TASO the advantage of showcasing their latest research finding and gaining exposure as a quality care provider.

In addition to evidence-based decision-making and opportunities for international exposure, a more practical benefit of research projects involved the tangible resources which Northern partners provided for TASO during the projects. Respondents described how hosting projects with Northern partners created more job opportunities within TASO. As a strategy to maximize staff retention, respondents described a TASO policy currently being put into practice whereby all staff hired to work on research projects are employed directly by

TASO (i.e. paid through TASO on the TASO salary scale) to work on the research projects, in contrast with being hired independently by a Northern research project. This employment strategy strengthens the link between the staff hired on contract to work on the research projects and the TASO 'parent' (i.e. staff who are part of general TASO programming). Many research staff continue to work with TASO after completing their contract on the research project and join the 'parent' staff. This was perceived as a benefit because it provided both job security for the research staff and avoided 'brain drain' of trained research staff out of TASO. As one respondent describes:

> "The trickle down was that of course, that study gave people jobs. We got jobs. Because of the trial I got exposed [to research] and …after the assignment, the project ended but still we [were hired to] furthered the [research] goals of TASO."

Another tangible benefit from hosting research trials was access to supplemental ART treatment slots. Access to ARTs for seropositive clients is an on-going struggle in Uganda, and many of the North-South research projects at TASO involve evaluating the efficacy of a new drug or method for service delivery and have the potential to incorporate extra ART slots for TASO clients into their design. This tangible benefit was widely appreciated by all respondents because ART slots can be quickly incorporated into the clinical care program and immediately benefit clients.

Challenges to Engaging in the Research Process

Despite keen interest, there were still significant challenges to fully engaging in the research process. Barriers to data utilization emerged as a salient theme. Part one of the survey, examining acquisition of research, elicited a lot of comments surrounding skill deficits in data analysis. Several respondents mentioned that TASO has an abundance of data but lacks the ability to utilize it effectively. Analyzing data is a part of the research process that remains predominantly under the mandate of the Northern investigators. As one respondent describes:

> "…sometimes our data gets sent to [Northern researchers]. They do the analysis and then they send us the reports… But we should be able to have the capacity to do that… We need data analysis training as an organization, badly. Because we have so much data that we cannot even analyze."

Data entry is a routine part of program monitoring and evaluating and research projects carried out at TASO. After becoming proficient in data collection, many respondents wanted to upgrade their training to analyze data and inform the daily practices of the organization. Respondents described how having more control over this part of the research process would improve their research capacity.

Every respondent commented on the lack of time in his or her workday to dedicate to building research capacity at TASO. The information and technology (IT) department is responsible for entering program data and generating quarterly reports, but going beyond these operational responsibilities to identify branch research needs and researchable questions is subject to considerable time

limitations. The research committee operates on volunteerism, so time is always a concern because each member has a full time job (e.g. staff nurse, counsellor, data manager etc.) with its own tasks and responsibilities. In spite of these limitations, respondents described how they make time to meet and continue to support both research project and 'parent' staff with an interest in research. Respondents described the increasing interest of TASO staff to see the results from not only the research projects but also the routinely collected data beyond the standard reports. Researchable questions commonly emerge from staff and research committee members (as described below), but lack of resources such as an operating budget or human resources to conduct research was a common barrier to executing research activities. As one respondent describes: "Yes, but the problem with us is that sometimes we have good ideas, but there is a problem of resources."

In addition to lack of data analysis skills and resource constraints, respondents mentioned circumstances where dynamics within North-South research partnership minimized Southern engagement. When TASO had less of a role in the on-going research projects, they had fewer opportunities to participate in skill building and knowledge exchange. Respondents described maladaptive research practices where Northern researchers would establish a research project at a TASO branch but employ separate staff on different salary scales and operate independently from the branch members. The respondents mentioned that the main responsibility of the TASO branch was to refer clients to

the research project, and once the sample size was completed the branch members were no longer involved in the research.

One respondent described the division between the research project and the TASO branch - "If you go past certain points you will be questioned. You're not allowed. So somehow we are all in TASO but we are two different people." The respondents acknowledged that the research relationship was designed so that the primary role of the branch was to supply participants for the study, but they wanted the opportunity to be involved in and learn from the on-going project.

> "If they would involve staff in their work then that would enhance staff capacity. Because if you act with them you learn the skills they are doing, but it is not very common. They are very independent. There are certain points where staff have been banned, so somehow the staff are not familiar."

Despite hosting very complex projects, the research capacity that was transferred to the TASO branch and among the members was minimal in these cases.

Aspiration for Southern Initiated Research

> "But if we are able, because we have the resources, we have the educated people, we know what it takes… surely, certainly, I want to believe we have the capacity to do it without too much involvement from the Western people."

A prominent theme among the respondents was the motivation to expand beyond 'hosting' global research projects to designing and initiating their own research projects. Many of the respondents had gained experience working on research projects at TASO branches and now wanted to apply their research

skills outside of the context of a Northern-led research project. As described

above, respondents commonly mentioned the magnitude of data accumulating at

TASO through the program database. The research committee wanted to use

TASO data and develop researchable questions and look for trends among

TASO clients. As one research committee member says:

> "Some people are interested and they come up and say yes, I would like to find out how many mothers are on ART and have given birth to children, and how their children are progressing. Things like that at the local level."

Others were interested to go beyond program monitoring and evaluation

to include formal investigations of unexplored topic areas using techniques inline

with community-based participatory research. As one respondent describes a

proposed project idea:

> "We can go to [this village] and interact with [the villagers] and see what is happening, so that would be research. Then [through] the interaction [we] would then come back and develop a proposal. Identify a few people go down there and train them to do what? To help their people."

These examples were described as independent TASO projects, initiated and

conducted using their own skills and data.

A commonly cited example of TASO-driven research was the

development of the abstract committee. A training session on writing abstracts

had been provided to selected TASO staff, teaching them how to write scientific

abstracts and summarize research findings into a small concise document

divided into introduction, methods, results and conclusions. The recipients of this

training quickly understood the utility of this skill and developed an abstract

committee to teach it to other TASO staff. Every TASO member (even clients) was encouraged to submit abstracts to the committee who would review and provide feedback. The research committees support the development of abstract writing at the branch level and then final abstracts are approved at the Head Quarter level before submission to conferences. One respondent describes the process of writing an abstract:

> "As we do the research we write abstracts, and when I write an abstract I present it to few people to add value to my abstract. And what I've done as an individual should at least benefit the general staff. Then we can own it as our research question. We should own it, that's how I feel."

To demonstrate the success of this initiative, TASO submitted sixty abstracts to the International AIDS Society Conference 2010 (to be held in Vienna, Austria from the 18-23 of July); thirty-nine were accepted as posters or oral presentations, and fifteen presenters received scholarships. Many of these abstracts used data from the formal research projects with global partners, but many abstracts were written from TASO-driven initiatives and research questions. Through this activity they have built research capacity to analyze and disseminate research findings, but have also ensured that writing abstracts remains an accessible skill to all interested TASO members as even clients can submit abstracts.

DISCUSSION

The literature on North-South research partnerships commonly concludes with a need to focus on strategies to build Southern capacity in their own country (4, 5, 8, 11, 13, 14, 38-41), but unfortunately there are very few examples documenting the successful application of strategies used to overcome research capacity barriers. This study describes the challenges to building Southern research capacity but also the benefits, and concludes with an alternative example (i.e. not Northern initiated) for Southern building research capacity where the Southern partners take ownership over the research process and develop a research agenda reflective of their interests and goals.

TASO has been hosting several complex and innovative research projects. These projects have supported evidence-based decision making for their program planning and have provided opportunities to develop research capacity at TASO through hands-on experience with different components of the research process. Participating in research projects provide valuable benefits that allowed TASO to leverage its credibility when advocating for best practices at the policy level both within the organization and at the national level. With the results from these studies TASO staff were able to present their findings at international conferences. This provided Southern researchers with valuable international experiences for gaining research capacity and acquiring knowledge

in different content areas. Northern-led research projects also had the tangible benefit of providing jobs for TASO staff and ARTs for TASO clients.

Although TASO hosted many research projects it was not always included or actively involved at each stage of the research process. At times its role in the North-South research projects was primarily to amass a cohort of research participants, after which it were expected to have limited involvement. In some circumstances TASO staff were even banned from entering the research site. Despite a keen interest to learn more about research methodology and to be more engaged in the research study, there was little room for further collaboration. Outside Northern-led research, TASO had difficulty utilizing the data it was accumulating through the program planning. There was a skill deficit among TASO staff to conduct data analysis and as a result they were unable to produce reports or analysis beyond quarterly monitoring and evaluation.

The combination of hands on experience working on Northern-led research projects, having a database full of programming data, and a training session on how to write scientific abstracts sparked TASO's aspiration to create a space where the staff could begin to explore their own research questions. The development and success of the abstract committee is an empowering example of Southern partners capitalizing on the skills learned in a training session to develop their own research agenda. This study captures the evolution of a Southern institute from being a 'host' of Northern-led research studies to broadening its role to include being an 'investigator' and concurrently developing a Southern-initiated research agenda. The transformation from a passive

beneficiary to the more empowered agent of change has been documented among global development studies in general and particularly in response to aid (42, 43), and also applies in the development of research capacity. This example illustrates of the process undertaken by a Southern organization to develop local research capacity and undertake studies in its own national setting.

This study provides valuable complementary literature to the existing body of work on research capacity building about which there is a dearth of information from the perspective of the Southern partner. Although the primary author is a Northern investigator, this topic was self-identified by the Southern partners as a priority area; the project was jointly designed and executed, and the analysis is grounded in the voices of those involved in research at a Southern organization.

After the data was collected, a preliminary report (See Appendix 6) based on the field notes was written and returned to the organization. This report was circulated to all participating branches that used it and the survey as a guide to inform the development of a research agenda at each site. This process was supported by a small grants fund. Now each branch in collaboration with their regional partners has developed a strategic plan for building local research capacity. They are currently writing a proposal and budget for a research project on their identified topics of interest.

LIMITATIONS

The qualitative data in this study was not double-coded by another investigator and as such lowers the reliability of the findings. In this study the Southern researchers did not conduct the data analysis, but rather corroborated that results accurately reflected their experience with research at TASO. This is consistent with the reported skill deficit in data analysis and lack of time to provide training in qualitative data analysis. Because this study is primarily qualitative in nature, we are not able to establish causality, and there is the potential for low replicability. The method is easily replicated as all participants were primed with the same questionnaire, but individual experience and reactions to research are subject to variability and different priorities could emerge with a different sample of respondents.

It is important to acknowledge the neo-colonial dynamics that are at play in this study. Although there was considerable Southern involvement throughout the course of this study (from inception to dissemination), it was still conducted in a style similar to rapid/participatory assessment where a Northern investigator collected the data in a short timeframe and analyzed the data in the North. Great lengths were taken to ensure that the research partnership was as equitable as possible which included negotiating terms of reference for all stages of the research process and constant communication. This ensured that the research

conducted was relevant to TASO and the findings were utilized to improve

research capacity.

IMPLICATIONS FOR PUBLIC HEALTH PRACTICE

The methods used in this study are useful for generating ideas and opinions surrounding research capacity; the survey is very thorough and user-friendly in a resource-limited setting. It presents a model of the necessary components of the research process and allowed the participants to compare and contrast their experience to this model. Participants commented very fluently with minimal probing after completing the survey, which then acted as a useful tool for their future research capacity development. The results identified in this study reflect areas where both Southern and Northern partners can contribute to the research process. The Southern partners are capable of initiating research capacity building activities and do not have to wait for their capacity to be 'built' by the Northern partners. The greatest demonstration of building research capacity came from the Southern partners deciding to institutionalize research into their organization (i.e. research committees, abstract committees, institutional review boards, research officer positions). Northern investigators can ensure that current research practices capitalize on opportunities to build research capacity within Northern-led research projects by including Southern partners in all aspects of the research process. Moreover, they can support Southern partners to explore their research interests and develop a Southern-led research agenda.

Mechanisms for change

There are three particular junctures in the research process that merit consideration for further research as they most heavily support the integration of capacity building strategies into North-South research endeavours: 1) Donors' agendas and priorities trickle down through all research and development projects. Thus, if donors prioritize and mainstream research capacity-building for southern partners into the funding eligibility criteria for global health, northern researchers with less experience in research capacity building will be encouraged to become informed and integrate it into their research practice. The role of the donor in research capacity building has been widely iterated in the literature (38, 39, 44); 2) IRB's that review research conducted in global South can begin to look beyond standard ethical guidelines (e.g. participant protection) to include an evaluation of the dynamics of the partnership (14, 16, 31, 40, 45). There is a dearth of information on the ethical relations between North-South organizations conducting research, as much of the literature focuses on the protecting of Southern participants in Northern-led trials. With further progress, ethics boards could serve as an important mechanism to promote equity between researchers; 3) Signing a memoranda of understanding (MoU) is a practical means to secure an agreement between two organizations concerning the importance of research capacity building to a partnership (46). The MoU can serve as an important mechanism for Southern partners to advocate for the inclusion of research capacity building activities and support to develop their own research agenda.

While these three junctures offer distinct examples for where research capacity building can be incorporated into the North-South research process, it is important to recognize that northern investigators do not have to wait for bureaucracies (i.e. donor organizations and ethics boards) to revise protocol. Instead they could unilaterally become active in prioritizing Southern research capacity building. All organizations engaged in North-South research stand to gain tremendously by including mechanism to mediate the inherent power asymmetries of North-South relationships into their future research. The survey used in this study offers insight into different components of the research process and elucidates the building blocks for using research in a health setting. The Canadian Coalition for Global Health Research published the "Partnership Assessment Toolkit" which was developed with extensive Southern consultation to foster research partnerships that lead to equity (27). This toolkit is thorough and user-friendly, and provides a framework for discussing all aspects of the research process from inception to exit strategies. The inclusion of this level of consideration into research partnerships and design will lay the foundation for a truly sustainable Southern research agenda led by Southern investigators.

CONCLUSION

As global health research proliferates, it is critical to ensure that North-South research partnerships ultimately lead to improved health outcomes, greater program impact, and greater equity between researchers in the domain of global health. Incorporating Southern research capacity building into research project design, from inception to exit, will maximize the integrity of global health research and strengthen the ability of Southern organization to incorporate findings into action.   This study documents how TASO uses research for decision-making at the organizational level, as leverage to influence public policy at national level, and to gain exposure as Southern leaders in HIV/AIDS care at the international level. After hosting several Northern-led research studies, TASO has taken on their own role as investigators conducting Southern-led research, despite limited resources and time. Supporting the development of Southern research capacity that includes a strong voice from the global South will provide a foundation for a progressive research agenda rooted in Southern knowledge systems. Lack of meaningful involvement of the global South in research will ultimately lead to lack of community and individual benefits from the initiated research programs (47).

REFERENCE LIST

References

1. Slater D. Geopolitical imaginations across the North-South divide: issues of difference, development and power. Political Geography 1997;16(8):631-653.

2. Bhagwati J. Ideology and North-South relations. World Development 1986;14(6):767-774.

3. Reuveny RX, Thompson WR. The North-South divide and international studies. International Studies Review 2007;9(4):556-564.

4. Costello A, Zumla, A. Moving to Research Partnerships in Developing Countries. British Medical Journal 2000;321:827-9.

5. Baud ISA. North-South Partnerships in Development Research: An institutional approach. International journal of Management and Sustainable Development 2002;1(3):153-170.

6. Ansari WE. Collaborative Research Partnerships with Disadvantaged Communties: Challenges and potential solutions Public Health 2005;119(9):758-770.

7. UN. Strengthening the Global Partnership for Development in a Time of Crisis. New York: United Nations; 2009.

8. Jentsch B. Making Southern Realities Count: Research agenda design in North-South collaborations. Social Research Methodologies 2004;7(3):259-269.

9. Jentsch B, Pilley, C. Research Relationships Between the South and the North: Cinderella and the ugly sisters? Social Science and Medicine 2003;57:1957-1967.

10. Edejer TTT. North-South Research Partnerships: The ethics of carrying out research in developing countries. British Medical Journal 1999;319:438-41.

11. Houtondji PJ. Producing Knowledge in Africa Today the Second Bashorun M. K. O. Abiola Distinguished Lecture. African Studies Review

1995;38(3):1-10.

12. Smith L. Decolonising methodologies. New York: Zed Books; 1999.

13. Lairumbi GM, Molyneux S, Snow RW, Marsh K, Peshu N, English M. Promoting the social value of research in Kenya: Examining the practical aspects of collaborative partnerships using an ethical framework. Social Science & Medicine 2008;67(5):734-747.

14. Dickert N, Sugarman, J. Ethical Goals of Community Consultation in Research. Health Policy and Ethics 2005;95:14-19.

15. Wallersteing NB, Duran, B. Using Community-Based Participatory Research to Address Health Disparities. Health Promotion Practice 2006;7(3):312-323.

16. Buchanan DR, Miller, F.G., Wallerstein, N. Ethical Issues in Community-Based Participatory Research: Balancing Rigorous Research With Community Participation in Community Intervention Studies. Progress in Community Health Partnerships: Research, education and action 2007;1(2):153-160.

17. Pinto RM, Schmidt, C.N.T., Rodriguez, P.S.O., Solano, R. Using Principles of Community Participatory Research: Groundwork for a collaboration in Brazil. International Social Work 2009;50(1):53-65.

18. Karmaliani R, McFarlane J, Asad N, Madhani F, Hirani S, Shehzad S, et al. Applying community-based participatory research methods to improve maternal and child health in Karachi, Pakistan. Nursing Outlook 2009;57(4):204-209.

19. Johnson CE, Ali SA, Shipp MPL. Building Community-Based Participatory Research Partnerships with a Somali Refugee Community. American Journal of Preventive Medicine 2009;37(6, Supplement 1):S230-S236.

20. Durst D. Partnerships with Aboriginal Researchers: Hidden pitfalls and cultural pressures. Saskatchewan Institute of Public Policy 2004.

21. Baber Z. Colonizing nature: scientific knowledge, colonial power and the incorporation of India into the modern world-system. The British Journal of Sociology 2001;52(1):37-58.

22. Rakowski CA. The Ugly Scholar: Neocolonialism and ethical issues in international research. The American Sociologist 1993;24(3-4):69-83.

23. Rigney LI. Internationalization of an Indigenous Anticolonial Cultural

Critique of Research Methodologies: A Guide to Indigenist Research Methodology and Its Principles. Wicaza Sa Review 1999;14(2):109-121.

24. Snarch B. Ownership, Control, Access and Possession (OCAP) of Self-Determination Applied to Research. Journal of Aboriginal Health 2004;1(1):80-95.

25. McCoy D, Sanders, D., Baum, F., Narayan, T., Legge, D. Pushing the International Health Research Agenda Towards Equity and Effectiveness. Lancet 2004;364:1630-31.

26. Nchinda TC. Research capacity strengthening in the South. Social Science & Medicine 2002;54(11):1699-1711.

27. Afsana K, Habte, D., Hatfield, J., Murphy, J., Neufeld, V. Partnership Assessment Toolkit. Canadian Coalition for Global Health Research 2009.

28. TASO. The AIDS Support Organization.   [cited 2010 17 June]; Available from: http://www.tasouganda.org/

29. TASO. The AIDS Support Organziation: Five Year [2008-2012] Strategic Plan. Kampala, Uganda: TASO; 2008.

30. NIH. Guidelines for the Conduct of Research Involving Human Subjects. U.S. Department of Health and Human Services 2004;National Institute of Health.

31. Schnarch B. Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities. Journal of Aboriginal Health 2004:1-16.

32. CHSRF. Is Research Working for You? A Self Assessment Tool and Discussion Guide For Health Service Management and Policy Organizations: Canadian Health Service Reseach Foundation; 2007.

33. Kothari A, Edwards N, Hamel N, Judd M. Is Research Working for You? Validating a Tool to Examine the Capacity of Health Organizations to Use Research. Implementation Science 2009;4:46.

34. Thornhill J, Judd M, Clements D. CHSRF Knowledge Transfer: (Re)Introducing the Self-Assessment Tool That Is Helping Decision-Makers Assess Their Organization's Capacity to Use Research. Healthcare Quarterly 2009;12(1):22-24.

35. SAS 9.2 Software, North Carolina; 2009.

36. Ltd QIP. NVivo 8. In. Cambridge, MA; 2000. p. Software for Qualitative Analysis.

37. Weidle PJ, Wamai N, Solberg P, Liechty C, Sendagala S, Were W, et al. Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. The Lancet 2006;368(9547):1587-1594.

38. Connolly P, York, P. Evaluating Capacity-Building Efforts for Nonprofit Organizations. OD Practitioner 2002;34(4):33-39.

39. Currie M, King, G., Rosenbaum, P., Law, M., Kertoy, M., Specht, J. A Model of Impacts of Research Partnerships in Health and Social Services. Evaluation and Program Planning 2005;28(4):400-412.

40. Simon C, Mosavel M, van Stade D. Ethical challenges in the design and conduct of locally relevant international health research. Social Science & Medicine 2007;64(9):1960-1969.

41. Sitthi-Amorn C, Somrongthong, R. Strengthening health research capacity in developing countries: a critical element for achieving health equity. British Medical Journal 2000;321(7264):813-817.

42. Gill K. From beneficiaries to change agents: the rise of women's leadership in international development. SAIS Review of International Affairs 2009;29(2):23-38.

43. Moyo D. Dead Aid: Why Aid is not working and how there is a better way for Africa: Douglas & McIntyre; 2010.

44. Bozzo SL. Evaluation Capacity Building in the Voluntary/Non-Profit Sector. The Canadian Journal of Program Evaluation 2002;17(3):75-92.

45. EARDC. Fair Benefits for Research in Developing Countries. Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries 2001;Policy Forum: Ethics.

46. De Savigny D, Kasale, H., Mbuya, Reid, G. Fixing Health Systems (2nd Edition); 2008.

47. First Nations Centre, National Aboriginal Health Organization. Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities Ottawa, Ontario; 2007.

APPENDICES

Appendix 1: Simon Fraser Ethical Approval

From: Hal Weinberg <hweinber@sfu.ca>
Subject: **[2009s0442] Minimal Risk**
Date: November 28, 2009 10:56:49 AM PST (CA)
To: dmoore@cfenet.ubc.ca, robert_hogg@sfu.ca, kam29@sfu.ca, kshannon@cfenet.ubc.ca, emills@cfenet.ubc.ca
Cc: dore@sfu.ca
▶   2 Attachments, 200 KB

SFU | SIMON FRASER UNIVERSITY
THINKING OF THE WORLD

ORE
Office of Research Ethics

H. Weinberg, Ph.D.
Director, Office of Research Ethics
Simon Fraser University

8888 University Drive
Multi-Tenant Facility
Burnaby, B.C. Canada, V4A 1S6
778 782 6593

Date:_____ 28 November 2009

File:_____ [2009s0442]
Approval_____ Approved

Principal Investigator (PI):_____Muldoon, Katherine

Project Risk:_____ Minimal

Title:_____ Building research-capacity through Canadian-Ugandan HIV/AIDS research collaborations

SFU Status of PI:_____Graduate Student
Supervisor:_____Hogg, Robert
Department:_____Health Sciences

Project Start Date:_____ 28 November 2009
Project End Date:_____28 November 2012

Hello Katherine,

Your application has been categorized as 'minimal risk'' and approved by the Director, Office of Research Ethics, on behalf of the Research Ethics Board in accordance with University policy R20.0, http://www.sfu.ca/policies/research/r20-01.htm.
The Board reviews and may amend decisions made independently by the Director, Chair or Deputy Chair, at their regular monthly meetings.

Please acknowledge receipt of this Status Notification by email to: dore@sfu.ca
Please include the file number in brackets, and include brackets, as the first item in the subject line, e.g., [2009s0000]

You should get a letter shortly. Note: All letters are sent to the PI addressed to the Department, School or Faculty of Simon Fraser University,as it is shown in the application. Graduate Students should check their Graduate Student Mailbox. Letters sent to Undergraduate Students will be sent to their Faculty Supervisor.

Good luck with the project

Hal Weinberg, Ph.D.

Appendix 2: University of British Columbia Ethical Approval

The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK

PRINCIPAL INVESTIGATOR:	INSTITUTION / DEPARTMENT:	UBC BREB NUMBER:
David Moore	UBC/Medicine, Faculty of/Medicine, Department of/Infectious Diseases - Med	H09-02672

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

Institution	Site
N/A	N/A

Other locations where the research will be conducted:
The AIDS Support Organization (TASO) located in Kampala, Uganda. TASO is the largest and oldest indigenous non-governmental AIDS service organization in Africa. Interviews will take place at TASO Head Quarters.

CO-INVESTIGATOR(S):

Robert S. Hogg
Kate Shannon
Edward Mills

SPONSORING AGENCIES:

N/A

PROJECT TITLE:
Building research-capacity through Canadian-Ugandan HIV/AIDS research collaborations

CERTIFICATE EXPIRY DATE: November 3, 2010

DOCUMENTS INCLUDED IN THIS APPROVAL:	DATE APPROVED: November 3, 2009	
Document Name	**Version**	**Date**
Protocol:		
Research Capacity Ethics Proposal	3	October 29, 2009
Consent Forms:		
Research Capacity Consent Form	3	October 29, 2009
Advertisements:		
Information Recruitment Form	N/A	October 20, 2009
Questionnaire, Questionnaire Cover Letter, Tests:		
Focus Group Discussion Guide	2	October 20, 2009
Is Research Working For You? A Self Assessment Tool	N/A	October 4, 2009

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Appendix 3: Ugandan Virus Research Institute Ethical Approval

Tel: (256) 414- 321962 (Direct)
      (256) 414- 320385/6 (General)
Fax: (256) 414- 320483
Email:directoruvri@ug.cdc.gov

UGANDA VIRUS RESEARCH
INSTITUTE (SEC)
P.O.Box 49 ENTEBBE (U)

THE REPUBLIC OF UGANDA

Our Ref : GC/127/11/09/11
Your Ref:

23rd November 2009

Dr. David Moore, Josephine Birungi, Ms. Katherine Muldoon,

RE: UVRI SEC protocol titled **"Building Research-capacity through Canadian-Ugandan HIV/AIDS Research Collaboration."**

Thank you for submitting the above study dated 27th October 2009 to the UVRI Science and Ethics Committee (SEC)

This is to inform you that after expedited review of your study, UVRI SEC approval has been given for you to conduct your research.

Annual progress report and request for extension or end of study report should be submitted to UVRI SEC before the expiry of one year after initial date of approval i.e. by 23rd November 2010.

You can now commence data collection after registration of your study with the Uganda National Council for Science and Technology (UNCST).

Wish you the best of luck.

Yours sincerely,

Tom Lutalo
Chair, UVRI SEC

C.C   Ag. Director, UVRI
       Secretary, UVRI SEC

Appendix 4: The AIDS Support Organization Institutional Approval

The AIDS Support Organisation
TASO (U) Ltd.

TASO Headquarters, Mulago
P. O. Box 10443, Kampala
Tel: 0414 532 580
        0414 532 581
Fax: 0414 541 298
Email: mail@tasouganda.org

The Chairperson,
UBC Office of Research Services
TEF III Building
P.o.Box 102 – 6190 Agronomy Road
Vancouver, BC V6T 1Z3
(604) 822 – 8581

21st October 2009

Dear Sir/Madam,

Re: **Building research-capacity through Canadian-Ugandan HIV/AIDS research collaborations**

We have reviewed a request from Katherine Muldoon about questions to the above mentioned research proposal.
This gives her permission to come to TASO and conduct semi-structured interviews, focus groups discussions, and a synthesis workshop on research capacity with TASO staff who have been involved in research activities.

Yours faithfully,

Mr. Mwesigwa Robert
Director Planning and Strategic Information Directorate
TASO Headquarters

Appendix 5: Survey Descriptive Statistics

Part 1:	Acquisition of Data	Mean	Median	S.D	Min	Max
1.1 Are we able to Acquire Research?						
	We have skilled staff for research	3.50	4.00	1.03	2.00	5.00
	Our staff has the the resources to do research	3.06	3.00	0.92	2.00	4.00
	Our staff has the incentive to do research (it is used in our decision making)	2.81	3.00	0.98	1.00	4.00
	We have arrangements with external experts who search for research, monitor research, or do research for us.	2.81	2.00	1.17	1.00	5.00
	Our staff has enough time for research	2.46	2.00	0.99	1.00	4.00
1.2 Are we looking for research in the right places?						
	We work with researchers through formal and informal networking meeting with our staff	3.60	4.00	1.30	2.00	5.00
	We learn from peers through informal and formal netowkrs to exchange ideas, experiences, and best practices	3.47	4.00	1.30	1.00	5.00
	We get involved with researchers as a host, decision-maker partner, or sponsor	3.14	3.50	1.51	1.00	5.00
	We look for research in journals	2.93	3.00	1.03	1.00	4.00
	We look for information on websites	2.40	2.00	1.45	1.00	5.00
	We look for research in non-journal reports	2.27	2.00	1.10	1.00	4.00
	We look for research in databases by subscription	2.07	2.00	1.10	1.00	4.00

Part 2:	Assess					
2.1 Can we tell if the research is valid and of high quality?		Mean	Median	S.D	Min	Max
	Our organization has arrangements with external experts who use critical appraisal skills and tools to assess methodology and evidence reliability and to compare methods and results	3.56	4.00	1.26	1.00	5.00
	Staff in our organization has critical critical appraisal skills and tools for evaluating the quality of methodology used in research	2.63	2.00	0.96	2.00	5.00
	Staff in our organization has the critical appraisal skills to evaluate the reliability of specific research by identifying related evidence and comparing methods and results	2.50	2.00	0.82	2.00	5.00
2.2 Can we tell if the research is relevant and applicable						
	Our staff can relate our research to our organization and point out similarities and differences	3.75	4.00	0.86	2.00	5.00
	Our organization has arrangements with external experts to identify the relevant similarities and difference between what we do and what the research says	3.38	4.00	1.09	2.00	5.00

Part 3:	Adaptation					
3.1 Can we summarize results in a user-friendly way?		Mean	Median	S.D	Min	Max
	Our organization has arrangements with external experts who use research communication skills to provide recommended action to our decision makers	3.31	3.00	1.08	2.00	5.00
	Our organization has arrangements with external experts who use research communication skills to link research results to key issues facing our decision makers	3.19	3.00	1.11	2.00	5.00
	Our organization has arrangements with external experts who use research communication skills to synthesize in one document all relevant research, along with information and analyses from other sources	3.06	3.00	1.18	1.00	5.00
	Our organization has enough skilled staff with time, incentives, and resources who use research communication skills to present research results concisely and in accessible language	3.00	3.00	1.03	1.00	4.00
	Our organization has arrangements with external experts who use research communication skills to present research results concisely and in accessible language	2.94	2.50	1.39	1.00	5.00
	Our organization has enough skilled staff with time, incentives, and resources who use research communication skills to link research results to key issues facing our decision makers	2.63	2.00	2.00	2.00	4.00
	Our organization has enough skilled staff with time, incentives and resources who use research communication skills to provide recommended actions to our decision makers	2.50	2.00	0.73	2.00	4.00
	Our organization has enough skilled staff with time, incentives, and resources who use research communication skills to synthesize in one document all relevant research, along with information and analyses from other sources	2.38	2.00	0.81	1.00	4.00

1

Part 4:	Apply					
4.1 Do we lead by example and show how we value research use?		Mean	Median	S.D	Min	Max
	We communicate internally in a way that ensures there is information exchanged across the entire organization	4.13	4.00	0.50	3.00	5.00
	Our corporate culture values and rewards flexibility, change, and continuous quality improvement with resources to support these values	3.81	4.00	0.91	2.00	5.00
	The management of our organization has clearly communicated our strategy and priorities so that those creating or monitoring research know what is needed in support of our goals	3.44	4.00	1.09	1.00	5.00
	Our organization ensures staff is involved in discussioins on how research evidence relates to our main goals	3.25	4.00	1.13	1.00	5.00
	Our organization has committed resources to ensure research is accessed, adapted, and applied in making decisions	3.06	3.00	1.00	1.00	4.00
	Using research is a priority in our organization	2.81	3.00	1.33	1.00	5.00
4.2 Do our decision-making processes have a place for research?						
	Staff and appropriate stakeholders are informed of how available evidence influenced the choices that were made in our organization	3.69	4.00	1.01	2.00	5.00
	Our management team evaluates the feasibility of each option, including potential impact across on the organization as well as on clients, partners, and other stakeholders	3.56	4.00	1.03	1.00	5.00
	Decision makers in our organization give formal consideration to any recommendations from staff who have developed or identified high-quality and relevant research	3.50	4.00	0.89	2.00	5.00
	Staff and appropriate stakeholders receive feedback on decision, with a rationale for the decision	3.19	3.50	1.10	1.00	5.00
	Staff and appropriate stakeholders contribute evidence and know how that informatoin will be used	2.93	3.00	0.96	1.00	4.00
	Staff and appropriate stakeholders know when and how major decision will be made	2.75	3.00	1.00	1.00	4.00
	When we make major decision, we usually allow enough time to identify researchable questions and create/obtain, analyse, and consider research results and other evidence	2.69	2.50	1.08	1.00	4.00
	Relevant on-staff researchres are made part of decision -mkaing discussions	2.69	3.00	0.87	1.00	4.00
	Staff who have provided evidence and analysis usually participate in decision-making discussions	2.63	2.00	1.02	1.00	5.00

2

Appendix 6: Initial Report: Building Research-capacity through Canadian-Ugandan HIV/AIDS research collaborations

CENTRE FOR EXCELLENCE IN HIV/AIDS
&
THE AIDS SUPPORT ORGANIZATION

Building research-capacity through Canadian-Ugandan HIV/AIDS research collaborations

Narrative Report
Date: December 2009

1. Introduction

Research partnerships between high-income countries (HIC) and low-income country (LIC) are a common approach to conducting global research. However, there is a clear disparity between HIC and LIC in both research capacity and the resources. The AIDS Support Organization (TASO) and the BC Centre for Excellence in HIV/AIDS have been working together to form a collaborative research agenda. One of the prominent research projects is the Highly Active Antiretroviral Treatment as a Prevention Tool Study, also known as the HAARP Study that is being conducted at TASO-Jinja. Through the HAARP study emerged an interest in not only conducting research at TASO, but using research as a vehicle to building the research capacity of Ugandan staff and researchers.

Katherine Muldoon, a Masters in Public Health student from Simon Fraser University in British Columbia worked on the HAARP study from April-August 2009 and from that experience developed a small project to investigate research capacity at TASO. A proposal was written and submitted to the Simon Fraser University, University of British Columbia, and the Ugandan Virus Research Institute for ethical approval.

The proposal was designed to investigate TASO's research capacity by interviewing and providing a questionnaire to the research committee members at 4 different TASO branches, TASO-Mulago, TASO-Jinja, TASO-Mbale, and TASO-Masaka. It is designed to: 1) assess the baseline institutional research capacity of TASO; 2) identify the potential facilitators and barriers to building research capacity at TASO; and 3) explore how partnerships with international organizations affect TASO's research capacity.

2. Summary of Findings

This is a mixed methods explorative case study where participants were TASO employees and members of the research committee at the Mulago, Jinja, Masaka, and Mbale branches of TASO. The scientifically validated tool, "Is Research Working for You?" (Canadian Health Service Research Foundation) was administered to generate ideas about research capacity followed by an in-depth interview to capture impressions.

Nineteen research committee members from 4 TASO branches participated in the study. The participants held different jobs within TASO and had experience as either a support staff for a study or were directly involved as research staff. The following description is a preliminary analysis of the results. A more in-depth qualitative analysis will follow. The purpose of this report is merely to highlight commonly mentioned points and map the way forward

a) Staff level

A key point that was mentioned by most staff was the lack of human and physical resources to conduct research. Many staff were very interested in

conducting research studies (even on their own) but worked to full capacity and did not have time to develop research ideas on top of their normal workload. Some were concerned about diverting attention from patients if they became more involved in research projects.

Some of the main advantages the TASO staff reported was that research brought more funding and provided the opportunity for TASO to have more antiretroviral treatment slots, and in turn let them increase their client load. They became exposed to new ideas and the latest information about HIV care and treatment. Many noted that the studies on sero-discordant couples helped them identify new clients and their at-risk spouses so they could offer them additional care.

Many staff had an interest in writing abstracts and going to conferences to share results and learn from other researchers. Some reported that after finishing school there is not as strong a reading culture so it can be difficult to engage in highly academic projects. Participants reported that the right research is not just data collection but can be a motivation to strengthen their careers and their job performance. Many participants commented that not all staff are interested in research, and sometimes even the managers are not always so enthusiastic, perhaps because it competes with service delivery and standard TASO programs. Participants desired more information sharing, and would like to see more dissemination and possibly even a mentor program. One participant suggested evaluating how many people are actually interested in learning more about research and then offer trainings based on that assessment. Others suggested a research day each quarter where those who are participating in research get the chance to share ideas with other TASO staff. Sharing these ideas can help other staff generate ideas.

The PrEP trial was described as being a valuable study that is essential for discordant couples and they are looking forward to the results. Some of the challenges that staff face is that clients are paid very generously to participate in the research and they are worried that this might affect the clients motivation to return to TASO if they are not paid to come to the clinic for regular services. Some participants reported a division of efforts between the research site and the TASO clinic and at times the confidentiality of the research gets in the way of working together.

In general, many staff wanted to the chance to improve their research skills and felt this (lack of research skills) was the main reason that Ugandan nationals did not lead more of research that occurs on Ugandan soil. The largest gap that they reported was lack of skills in data analysis.

b) Patient level
The main benefit that staff felt the clients gained from participating in on-going research projects was financial compensation and for those in sero-discordant relationships, the chance for their negative spouse to receive care. Data from studies has been incorporated into programming such as drama and education for clients. Several TASO staff made the observation that at times TASO clients who participate in research studies are unclear of what they are doing. This is an

important observation. It was noted that TASO clients do not always feel comfortable participating in the research but do not know how to leave. Participants articulated that counselors can be an important pathway to assess if clients are really comfortable being in the research study. Perhaps client satisfaction with studies can be assessed through the counseling department.

c) *Institutional level*

Key institutional-level factors for building research capacity involved including research into the 5-year strategic plan. The strategic plan was often mentioned and gave the impression of organizational unity for creating space for a research department to grow. Another key institutional development was the TASO institutional review board, although newly formed has the ability to centralize research and allow TASO to review each proposal and assess how they can maximize their benefit from the research they participate in.

Many participants noted that TASO had a lot of data but is not able to use it to make changes yet. For example, one data manager mentioned that the statistic that only 30% of clients are men but they do not have the resources to address this problem. It was also descried as being "obvious" and therefore not so interesting. This supports the point that attendance at conferences and sharing inform with other researchers can provide enlightenment into the severity of the problem.

TASO works in collaboration with the Ministry of Health in Uganda and is in a position to inform health policy makes. TASO has been able to incorporate findings from several studies into their practice, especially the Medical Research Council (MRC) study of home-based versus on-site care. The initial results from this study proved that home-based care was less expensive for clients (because they did not occur transport costs) and less expensive for the clinical site. The Community Drug Delivery Points or CDDP Program was developed in a response to this finding. Despite these important successes of operationalizing study results, there is still a perceieved barrier for translating these results to the Ugandan MoH. Areas for future development can focus on this important link of translating successful research results beyond TASO to serve the greater Ugandan public.

Utilizing the memorandum of understand (MoU) can be a key institutional document to operationalize goals for building research capacity, especially what TASO wants to gain from the research process, and how it will be measured. This can be an important area to make sure systems are in place for utilization of the research findings.

d) *Global partner level*

Participants appreciated it when global research partners engaged in knowledge exchange, research skill and methodology training, and continuous communication of research findings and project status. When HIC researchers come for site visits it is valuable when they can offer trainings and provide insight into the research findings.

Some branches have received students from HIC to work on projects. The presence of the students of often appreciated. Student often conduct short studies or provide support for a short amount of time, but provide comprehensive reports when they leave. The presence of the students raises awareness of research issues especially when the results are presented to the whole group.

An important and commonly mentioned mechanism for building research capacity was the feedback loop. Some participants felt that information gets shared at the international level more than it does at the national Ugandan level.

3. Limitations
Many of the participants noticed that Dr. Birungi was not listed on the consent form. This was an important point that was the result of inflexible ethics boards in Canada and lack of time to address this point. Dr. Birungi is the Principle Ugandan Investigator on the study and should be on the consent forms. If there is a chance to submit an amendment we will update this omission.

4. Progress to date
With this preliminary analysis we have submitted an abstract to the International AIDS Society (IAS) Conference to be held in Vienna, Austria. With hope we will get the chance to present these emerging results and generate more discussion on building research capacity within HIC-LIC research partnerships.

5. The Way Forward
The next step for this project is to undergo an in-depth analysis with qualitative software. All interviews will be transcribed and uploaded into a statistical analysis program. From this point a procedure called "thematic analysis" will take place and key themes that emerge from the data will be summarized. The questionnaire data will be used to support the findings. It is estimated that the entire analysis and written report will be completed by June 2010. This will be the major project for Katherine Muldoon's Masters program. She is also compiling literature on research capacity building between HIC and LIC partners and will provide TASO with a book and electronic copies of these readings. We aim to conduct the second evaluation in December 2010, 12 months after the initial assessment. At this point we hope to conduct a workshop and present the results in order to have a discussion about what these findings mean, and how TASO can incorporate them into the strategic plan.

6. Conclusions
Despite hosting complex and innovative research studies, research capacity is not always translated to Ugandan researchers and institutions. Time and physical resources are the largest barrier to building capacity because there is a substantial interest from TASO employees to become involved in research projects. The TASO IRB is an important institutional structure to ensure the development of capacity at TASO. To achieve these goals, research capacity might have to be explicitly stated in more formal terms of reference.