

## It is harvest time at THRiVE Cambridge, but the great work must continue.....

It's been all smiles here in Cambridge, as five of the six THRiVE PhD fellows being mentored by our academics have either successfully defended their theses, or have already graduated this year! It is great to be witnessing the fellows reap the fruits of their labour, and we strongly applaud the fellows, their local supervisors/advisors, the Cambridge researchers as well as the THRiVE Secretariat and family for getting all these fellows safely across the finish line. We encourage all the remaining THRiVE fellows linked to both Cambridge and the LSHTM to finish hard! Also, all the fellows have been publishing their research, and the number of publications that have THRiVE Cambridge fellows and their Cambridge mentors as co-authors has hit the '20' mark. We look forward to seeing the numbers continue to rise, in the near future.

We have not forgotten about the

THRiVE postdoctoral fellows linked to Cambridge mentors, though. In January 2016, one of Dr Roman Ntare's Cambridge mentors - Dr Simon Frost, gave a presentation focusing on 'The Dynamics of Emerging Viruses in Africa' at one of our monthly Cambridge-Africa Seminars held at King's College in Cambridge. A section of his talk was about his collaborative research with Dr Ntare (the role of sexual networks and the transmitted virus in the spread of HIV in Rwandan at-risk populations), and generated a lot of interest and positive feedback. Dr Ntare then hosted the other Cambridge mentor - Dr Jane Grooten, on a visit to Rwanda in February 2016. This was very successful, and it was great for her to meet the local research team in Rwanda. The three researchers have submitted a manuscript on Dr Ntare's THRiVE project, and are hoping for a positive outcome. Drs Ntare, Frost and Grooten are also preparing



*Nana Ayebia Clarke MBE, Managing Director of Ayebia Clarke Publishing Limited, speaking about 'New Trends in African Publishing', at the King's/Cambridge-Africa Seminar organised in Cambridge on 21st April 2016.*

## Innovations and knowledge Translations Office: a platform for promoting utilisation of research evidence

By Dr. Ethel Nankya, IKT

Knowledge Translation Platforms (KTP) aim at facilitating uptake of scientifically sound research findings into action, bridging the know-do-gap. Knowledge Translation (KT) largely depends on collaborations and good interpersonal skills with relevant stakeholders. Many a time research findings are only disseminated through scientific publications which may not be accessible to the general public. Knowledge Translation can be applied through models described by Lavis et al. These models include the push, pull, exchange and integrated models. The Push model involves researchers packaging their findings using innovative delivery tools as a driving factor for change. The delivery tools include: videos, policy briefs, press releases etc. In this model, the decision makers are on the receiving end.

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Dear Reader,

## It is harvest time at THRiVE Cambridge

a joint proposal to seek funding to address HIV resistance testing in Rwanda, and aim to introduce deep sequencing technology into Rwanda (Dr Ntare had to sequence his current HIV samples in Cambridge when he visited in 2015, due to lack of this resource in Rwanda). They can then use the sequence data to understand transmission dynamics of HIV and identify effective public health interventions. We are very excited about this continued collaboration and the potential for long term impact in Rwanda and elsewhere.

While Cambridge is now excitedly looking forward to contributing to THRiVE-2, other Africa activities here continue apace. As an example, the umbrella Cambridge-Africa Programme hosted seminars on 'The Politics of Peace in the Great Lakes Region of Africa' in March, 'New Trends in African Publishing' in April, and 'Green urbanism and sustainable technologies in Rwanda' in May 2016. In addition, the 2016 call for the Cambridge-Africa ALBORADA Research Fund is open until 6th June. It has provided seed funding for several Cambridge and African research partnerships, and will run for 10 more years! Furthermore, to mark Africa Day in 2016, the Cambridge Africa Business Network (organised by MBA students interested in business in Africa) will run a

conference on 28th May, focusing on 'Transforming Africa: Creating Value & Driving Consumption'. The event will feature a fantastic line up of distinguished speakers and panellists from diverse businesses and organisations across Africa, including Standard Chartered Bank, Goldman Sachs, IC Publications, Deutsche Bank, SAB Miller, etc. The African Students Society in Cambridge will also be hosting their third annual 'Africa Together' event on 10th June, titled 'Engendering an Inclusive Africa'. The day will feature many prominent Africans making waves across the continent and around the world, who will speak about a range of issues reflecting the diversity of the continent. It is events like these that make Cambridge the exciting and rich cultural as well as scientific environment that will welcome the new THRiVE-2 PhD and postdoctoral fellows. May THRiVE continue to thrive, in this great University! Captions for photo

Nana Ayebia Clarke MBE, Managing Director of Ayebia Clarke Publishing Limited, speaking about 'New Trends in African Publishing', at the King's/Cambridge-Africa Seminar organised in Cambridge on 21st April 2016.

of these fellows regarding their experiences during the PhD fellowships. I hope that these stories will act as motivation for those following in their footsteps, take lessons and avoid similar challenges, learn how to minimize them or navigate around them should they occur. THRiVE might be well served if a systematic documentation and analysis is carried out to determine what factors lead to success and which are barriers during doctoral studies in the East African environment. Indeed, this is an area which calls for collaboration across different capacity building consortia, research institutes and universities. Interventions that are often cited as contributing to success include proactive use of a personal development plan, protected research time, course work, a supportive or facilitating research environment, excellent and caring supervisors and mentors. It is observed that some PhD students' research is embedded within a large ongoing study conducted by established research groups. And yet other students have to start from scratch to set up the infrastructure required to conduct a study successfully. These two different approaches of necessity involve different doctoral experiences but are expected to eventually lead to similar results, a competent graduate.

In this issue is a list of publications that have so far accrued from Wellcome Trust 6-year funding that is about to end. We need to career-track the beneficiaries of this funding right from masters level to PhD graduates, Post Doc fellows and those who received pump priming grants. There is need to know the career path these individuals are taking and also understand the products from the completed research including use of research results to impact local, national or global health policies and practice.

## Membership of the THRiVE Advisory Board

1. Prof. Wilfred Mbacham, Chair, Rest of Africa
2. Prof. Hannah Akuffo, Outside Africa
3. Dr. JPR Ochieng/Odero, Other Consortia
4. Prof. Jerome Kabakyenga, Uganda
5. Prof. Florent Senyana, Rwanda
6. Dr. Val Snewin, Wellcome Trust
7. Prof. Dominic Makawiti, Kenya
8. Dr. Hassan Mshinda, Tanzania
9. Prof. Nelson K. Sewankambo, Director, THRiVE
10. Dr. Saidi Kapiga, Deputy Director

## Innovations and knowledge Translations Office: a platform for promoting utilisation of research evidence

In the Pull model, the research users are key players and they request for research information while, the exchange model relies on collaborations between researchers and research users for mutual benefit.

The integrated model involves utilisation of knowledge translation platforms which act as institutional knowledge brokers. The platforms aim at linking the researchers and research users in a bid to promote dissemination and utilisation of research evidence. The Innovation and Knowledge Translations (IKT) office at Makerere University, College of Health Sciences adopted the integrated model. The IKT office packages what has been researched and written and disseminates it to the right audience where it will serve a practical purpose. It does this in several ways including, but not limited to, print media tools; these include policy briefs and policy releases.

One innovative delivery tool THRiVE I has utilised is the

media to disseminate research findings from the PHD fellows' work to the general public. This is particularly important in informing the general public about the scientifically sound research findings that may help them to make informed decisions about their health and health seeking practices. During this process, both the researcher and the journalists need to be brought on board. This entails convincing the journalist that you have a story that merits coverage and the researcher to create time.

Once both parties are on board, the IKT office critically appraises the research findings and packages the information in the simplest language that can easily be understood by a lay person. We simply the meaning of P-values, odds ratios, risk ratios in context without losing the intended message. The journalist then interviews the researcher using the press release as a guide for the interview that is aired.

The IKT office has managed to

disseminate four PHD fellows' work, who were supported by THRiVE using broadcasting networks like NTV and NBSTV and will continue to do so while engaging other networks, too.

The PHD fellows include:

- a) Ronald Kiguba: Medication errors, suspected adverse drug reactions and the use of herbal medicines was aired on NBSTV, January, 2016.
- b) David Meya: Immunopathogenesis of Immune Reconstitution Inflammatory Syndrome secondary to Central Nervous System Infections in HIV infected patients was aired on NTV, 27th December 2015.
- c) Moses Galukande: Breast cancer among Ugandan women: Delays in diagnosis, risk factors and survival. This was aired on NTV, 4th April 2016.
- d) Sam Ononge: Management of post-partum haemorrhage after childbirth in rural Uganda, Perceptions, risk factors

and effectiveness of antenatal distribution of misoprostol to women to self-administer. This was aired on NTV, 24th April 2016.

Worth to note is that for this strategy to be effective, and to have high output, researchers need to embrace knowledge translations' strategies aimed at having their work known by the end users; it is only when research findings are utilized by the intended end users that it becomes knowledge.

On the other hand, forming long lasting working relationships with the journalists is pivotal in this process. Training journalists in reporting scientific evidence and sensitizing them about their role in research evidence dissemination, and in utilizing research findings, are key for this strategy to be effective.

"A completed research project is like a seed. Getting the findings published in a scientific journal is like putting that seed in a packet, with a label on it. Well done! But is it a job done?"

## THRiVE PhD fellows' experience at the all African Institutions Initiative meeting

By Allen Kabagenyi

As one of the THRiVE PhD fellows I was privileged to attend the African Institutions Initiatives directors meeting in Cote D'Ivoire. The meeting brought together directors from about 7 consortia in Africa, welcome trust representatives, selected PhD and post-doctoral fellows. The well-attended two-day meeting was inaugurated with welcome remarks from Minister of health and the mayor of the town. The wellcome trust representative highlighted the need to learn from the past linkages for improved support to great innovative research. With an aim of building a critical

mass of excellent researchers in the region, Wellcome Trust promised to continue supporting innovative research that would improve/change peoples' lives.

A representative of the consortia noted that the 8 years of support from Wellcome Trust had led to a number of achievements with over 350 researchers supported in Africa to date. The well-organized sessions were characterized by presentation and discussions from consortia and selected fellows attending the meetings. Among the lessons learnt from the consortia was the need to: engage policy makers



Conclusively, the meeting was well organized with pointers to African Academy of Sciences and DELTAS that would be over seeing and supporting the new consortia. I am honored to have presented on behalf my team that was reporting on the tracking of PhDs and postdoctoral fellows.

and dissemination of research findings through media; focusing on women and widening scope to include maternal, neonatal and reproductive health; avoiding pseudo leadership and poor financial management; cooperation versus competition amongst the consortia and taking stock of policy impact.

The participants also learnt the main challenges faced by the network were the continuity amidst uncertainty of some consortia that had not received second round of funding, measurement of quality versus scientific excellence particularly of the PhD and post doctoral outputs. There was a suggestion of providing a mechanism to track postdoctoral and PhD fellows that had been supported by the trust.

# Accelerating Excellence in Science in Africa (AESAs) pays THRIVE a visit

News about the Accelerating Excellence in Science in Africa (AESAs) site visit to THRIVE could not fail to bring anxiety as would be expected of any funding agency visiting a grantee. Since the Wellcome Trust had earlier communicated that AESAs will be the implementing partner for the Developing Excellence in Leadership, Training and Science (DELTA) programs we felt it imperative to also invite the partner co-applicants and their Finance officers in order for them to have firsthand information on THRIVE 2 would run.

Led by the DELTA Africa Program Manager, Dr. Alponus Neba, the AESAs team which was composed of the finance and administration manager, grants officer and grants accountant was intended to lay the ground for the implementation of THRIVE-2 grant activities. 8th March 2016 being a public holiday could not deter the Makerere University central administration and the MakCHS leadership to fully participate in the site visit discussions. The Vice Chancellor Prof. Ddumba-Sentamu thanked the Wellcome Trust for supporting the core functions of the university which have contributed to increased research output and visibility. He reiterated the university's support in ensuring career pathways for fellows trained and protected time for research for the selected fellows. The Principal, MakCHS, Prof. Charles Ibingira commended THRIVE for impacting the entire university for last 5 years. He noted that the PhD and Postdoc fellows trained would contribute to research capacity building and also concretize research leadership.



Makerere University Vice Chancellor Professor John Ddumba-Ssentamu (front row centre) posing for a group photo with Professor Nelson Sewankambo (front row left), Professor Mukadasi Buyinza (front row second left) and Associate Professor Charles Ibingira (front row second right) with members of the DELTA program team and Makerere University staff during the visit

Over the two days of the site visit, the AESAs team engaged the THRIVE-2 team in fruitful deliberations on the role of AESAs, institutional support for program activities, governance, policies, requirements for monitoring and evaluation and financial arrangements. Dr. Nebba emphasized the need for a THRIVE-2 to ensure a health partnership not only between THRIVE-2 and the AESAs but also between THRIVE-2 and its partner institutions and other DELTA grantees. The AESAs team commended the 11 fellows who graced the meeting and shared their research findings for their eloquence in defending their work and for their ability to link their research findings to policy and practice.

THRIVE-2 is one of the 11 consortia provided with 5 year funding by the Wellcome Trust in partnership with the

Department of International Health and the AESAs to improve health in Africa through research focusing on national health priorities. THRIVE-2 will focus on research on infectious diseases, neglected tropical diseases, neonatal and reproductive health and non-communicable diseases. Despite the 6 year achievements, THRIVE still needs to pay attention to issues of merit versus equity, partner management and engagement and intellectual property and commercialization.



Taking a tour of some of the research training facilities available at Makerere University

# Risk Assessment; A Case for Development of a Risk Register

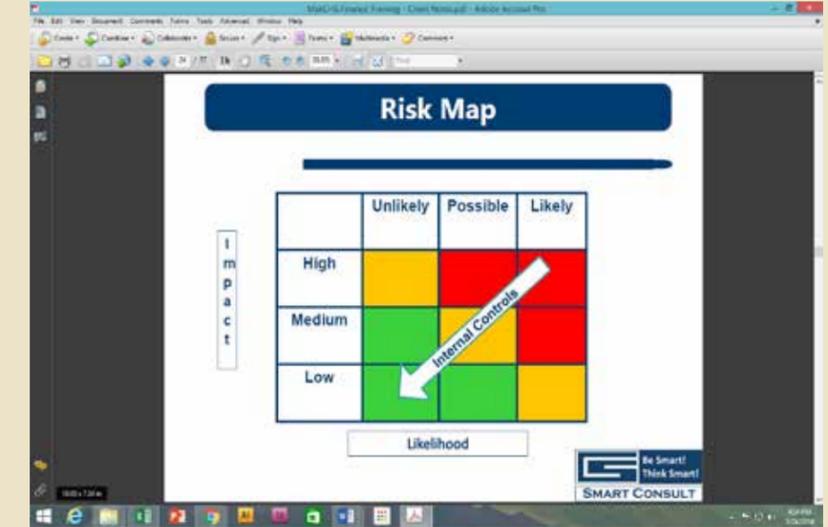
By Shem Wakaindha, David Kitunzi & Teefe Paul

Risk is the possibility of an event occurring that will impact the achievement of objectives.

It is very easy for one to associate risk with only the negative happenings or threats in our environment. However it is important to note that some risks manifest within a benefit. For example if one was offered a consultancy worth \$1 million per month to treat Ebola patients in a country where there is an outbreak. In this case, the funds on offer are the benefit especially for a health expert from a developing country and the threats are the chances that he or she will get infected with this highly infectious life threatening disease. On analysis the decision to take up the above venture will depend on ones ability to understand and respond to the risk embedded in it.

A risk can be Major, Moderate or Minor depending on the likelihood/ impact assessment. The impact and likelihood for the risk to occur put together may make the venture risky or not. However Internal controls may reduce the likelihood and impact of the risk.

(See Matrix below that can be used in measurement of each risk factor)



Source: THRIVE I Finance training by Smart Consult, June 2015

In developing a Risk Register, the first step is to understand your environment, and then identify risk factors surrounding it. For example trainee retention or loss of equipment, among others. The next step would be to categorise the risk factors into 2 major categories namely, the controllable and uncontrollable types. After categorization the next step would be to measure the risk using the likelihood (Unlikely, Possible & Likelihood) and impact (Low, medium & High) of the risk factor on attainment of program objectives.

On assessing each risk factor it is important to select an optimal risk response, by carrying out a cost-benefit analysis. A risk response can be categorized into risk avoidance, risk reduction, risk sharing and risk acceptance. However a response should be selected if it will either preserve or create value by reducing or eliminating the likelihood and/or impact of a risk. This can best be presented in a risk register (see template below)

### Sample of a risk register

RISK FACTOR	Measurement			Risk Response (Can be Preventive or detective)	
	CONTROLLABLE / UNCONTROLLABLE	Likelihood (Unlikely, Possible, Likely)	Impact (High, Medium, Low)		Overall (Minor, Moderate, Major)
1) Loss of Assets / Equipment	Controllable	Likely	High	Major	<ul style="list-style-type: none"> <li>Put in place physical protection</li> <li>Asset register</li> <li>Guidelines for use</li> <li>Insurance</li> </ul>

In order to be exhaustive in preparing a risk register you need to know your environment to come up with a comprehensive list of all risk factors associated with it. It's important to note that a risk register is not meant to deter someone from carrying out an activity but it simply provides the risk factor assessment and ability to respond to it in a preventive or detective manner.

# My Long and eventful Journey in this PhD.

By Ronald Kiguba (THRiVE PhD Fellow: 2011 - 2016)

I wake up in the morning to a reverberating elderly voice saying, "Time to go to school." It's about 5.00am and I can vividly recollect the tail-end of my interrupted dream envisaging the first day I will step into school with my new bag, a pair of brand new Bata shoes, a newly acquired container with two compartments; the lower one with flakes of buttered bread and the upper one with a "cocktail" of popcorn and ground nuts. In that moment, I do not quite understand this 'concept' - school. However, I am aware that my elder siblings always said "goodbye" to me whenever they left home for school every morning. Why can't I go to school with them? I always cried in anguish longing for the moment this 'school' experience would come true for me.

Well, then, here comes my real 'school moment'. Before long, I can confidently recite my favourite nursery rhythm! One after another, the nursery rhythms find space on my hard drive..and they consume the drive byte by byte. I have scarcely spent a term in school. Time loves to fly, and sometimes so fast. However, it is always a true story teller. I gradually realize that I have given up my rights and freedoms - given them up to routine! I can no longer pick up my car toys and drive anytime I want. The hip of sand in the home compound has lost my last few surviving footprints. I am seated on a wooden desk in baby-class painfully trying to understand the concepts of the English alphabet...A...B...C... "Oh my God, this is all so complex! Take me back home", I mutter to myself. In immediate response, my class teacher quips in a resonating voice, "Too late my dear." In total disbelief, I ask my teacher, "How did you manage to decipher what was in my mind?" The teacher replies, "It's very simple. You were thinking aloud! Now, can you give us the answer to the question I just asked?" "What was the question?", I reply to my teacher, "I never had the question!". The truth is that this is not an extension of my pre-school dream. It is a reality! My life has changed! Forever! Has it changed for the better? Well, that is a good

question, but one that might be difficult to answer in the very moment I realize that the honeymoon is over! I must now work hard!

I can always lend myself to these childhood moments. Picture me in that moment as one of the 14 THRiVE PhD candidates who have successfully made it through the grueling selection process. "You have made it! Eureka! You deserve it!", I would imagine one of you saying so to me.

Imagine me as an organized lad with the sort of research dreams bent towards solving the problems of the entire universe! In sub-study 1, I will interview all the healthcare professionals in Uganda. We shall trek the entire country. It's a small country after all! Didn't Christopher Columbus circumvent the whole world? How much larger is the World in relation to a measly Uganda? Nothing is impossible! In any case, the healthcare professionals' responses will give me an opportunity to identify all the problems related to the use of medicines in Uganda, including but not limited to their side effects. My research findings will surely provide solutions to all these problems. Sub-study 2: sometimes, it really helps to talk to the patients themselves! In any case patients are at the end of the food chain and they bear the brunt of all the terminal forces of healthcare. We shall make sure we recruit all the patients we encounter. We shall need numbers in this study that rally by the thousands! Yes, and in sub-study 3, we shall calculate the healthcare costs associated with these drug problems. I am a THRiVE fellow after all! I am not a student. Mark my words, "I am not a PhD student!" I am a PhD fellow!

To take my dream to another level, I am flown (along with other fellows) to an outside country to officially raise the curtain of my PhD journey. "Karibu!" The race is drawn to a start and off I start the expedition. "Uganda is so small and we must get all the healthcare professionals' interviews concluded within 3 months", I convince myself. My team and I soon realize that Uganda has some gentle hills, yes, and some steep ones too! The research journey is not going to be that easy after all! In

Scotland, what they call hills are in fact full-blown mountains! At some point, while tired and exhausted, we draw on some nursery school strength, "I think I can...I think I can"! And, ooh..hh! There is a more contemporary one ... "Yes we can!" Further on in our journey, I look at my watch and wonder if it skipped or gained time along the way. Is it really faulty? Is it truly 10 months down the road? Where did they all go? Uganda is such a small country! Well, at this point in time, we have drawn our lessons. Uganda is a big country after all! Well, we have managed to collect most of the information we need but from very small portions of the country; and with some 'furnace-fire' moments along the way.

Then we arrive at the wards to meet with our dear patients in sub-study 2. Who are the members of my team by this time? Well, they are pharmacists, physicians, medical officers, and degree nurses! These are my research assistants and I am in good company, aren't I? Yes! This phase of the journey demands a higher level of skill and I cannot risk embarking on it with a much less qualified team. Despite past hurts, I am in bullish mood once again aiming for nothing less than the highest bar! We get into cruise mode with the belief that the journey will be exciting - our target is to collect data from not less than 1,500 patients! Okay? Good. And remember, this goal must be achieved within 3 months! We have no worries at this time since Mulago hospital has a myriad of patients. After 3 months, the tally is, well, may be 200 patients and some of them were recruited in the first month and have just been discharged! Everyone has been working so hard, and by this time, we are exhausted. But the big question is, "Is there something wrong with the car we are cruising?" The current crisis of patient numbers notwithstanding, my highly skilled, smart, well-educated, intelligent research assistants walk into my office one morning in a solid team and their team leader presents a couple (and I mean two) of complaints. "First of all", the team leader mutters, "we

have put down our tools until our concerns are addressed". "Put down your tools?" I ask. "Yes", he retorts. "We work seven days a week and yet we are well-educated". To make matters worse, your study is so demanding and several of the study patients we recruit take long to be discharged. We want a pay rise!" "Pay rise?" I quip in disbelief. "Yes, and this ultimatum expires tomorrow since there are so many organizations that are seeking to utilize our expertise." By this time, I have had enough. I am travelling to London in a month's time to meet with my Cambridge supervisor and I need to have all the data. "The research assistants should get back to work and not complain. After all, I have already negotiated a good package for them. And what shall I do if they indefinitely turn their back on me? I will give up....I think.", I thought to myself. A vivid voice.... one bearing every quality and character of my nursery school teacher retorts... "It's too late to reverse this process my dear." I turn around looking for my nursery school teacher - desirous of asking her how she read my mind. Well, all I can see is my person telling me, "It's your PhD!" Immediately, I spring up with great gusto, with renewed strength and zeal. After an unprecedented intense moment of introspection there arises, within me, a new thought process....like a green shoot budding from a germinating bean seed. I find myself guiding a natural reorganization of the research team. The shake-up in its initial structure is gentle but itchy and uncomfortable enough to unsettle the ring-leaders of the strike. Those who are able to withstand the cosmic-driven transformation stay-on and the cruise momentum is rekindled! The research team becomes smaller but more efficient and yields double the amount of output previously obtained from the larger team. By this time, I am so exhilarated and with a renewed sense of maturity.

Certainly, there will be no immediate transition into sub-study 3 (economic evaluation), at least until sub-studies 1 and 2 are cemented, and a crown is received (which was received in March 2016) - at which point I say, "It was a good idea to dream in the first place."

I have mentioned so many "Is" in this discourse and perhaps would suffice to say.... It's more than just my PhD! It's a journey into the future. A journey intended to change, and certainly for the better, the lives of many generations!"

## An Early Career Researcher and his beautiful Encounter with the THRiVE-1 pump priming grants

By Adinan Juma (KCMUco) and Jenny Renju (LSHTM)



Juma Adinan is a medical epidemiologist and biostatistician. He trained at Kilimanjaro Christian Medical University College (KCMCo) for a medical doctor degree (2011) and Masters of Science in Epidemiology and Biostatistics (2014), the course which is supported by LSHTM under the sponsorship of THRiVE. Dr. Adinan is an early stage researcher and highly interested in pursuing and academic research career; he is interested in health systems and health services research. We asked Adinan to share some of his research experience with us:

"During my MSc training I had an opportunity of being involved in a THRiVE PUMP PRIMING Funded Self hypertension Assessment study (SHAS) as a coordinator, under the mentorship of Jenny Renju and Jim Todd. This opportunity not only provided me with important knowledge and skills in research, but also contributed a lot to my understanding and passion towards health systems and health services research."

Findings from the pump priming study (currently in-press) contributed largely in winning a grant for Advanced Research Training from the Medical Education Partnership Initiative (MEPI). This competitive grant provides me with some salary support which means I have protected time to pursue a mentored research project. The aim of my proposed research project is to improve management outcome of hypertension and is led by the following objectives; to describe health systems barriers and health systems factors associated with the availability and quality of hypertension services, to identify patients' level barriers and patient level factors associated with BP control, and to develop and pilot an intervention to improve hypertension control in hypertensives attending Kilimanjaro health facilities. It is my hope that we are going to accomplish the work ahead of us. On board are KCMU College researcher and physician, Rachel Manongi and Glory Temu respectively; Tanzania-based LSHTM research scientists; Jim Todd and Jenny Renju, Tanzania-based Cornell Medical University physician and researcher Rob Peck".

THRiVE support, training and mentorship has been instrumental in Adinan's research career development. He is a great ambassador for KCMUco and the THRiVE supported MSc in Epidemiology and Biostatistics. We look forward to supporting and following his research career.

## My PhD Journey.....standing on the shoulders of a giant



Moses Galukande

It was a bright sunny tropical day and we were making our way into the hospital to start our weekly major ward round. Unlike the usual way in which the boss gives a non verbal signal for the houseman to start presenting the first patient, he instead and abruptly so, asked the patient directly, 'So how old are you? She replied with considerable difficulty in a shaky voice, "26 years old sir". She had late stage breast cancer and it had spread to her lungs. It was not a sunny bright day for her.

The reference text books we read did say breast cancer was a disease of the 5th and 6th decades of life, a stark contrast with what we were seeing regularly in our practice. We all struggle with contradictions, but this was happening too often. Way too many young women with breast cancer were dying too early because they came in with late stage disease and we did not fully know why. This lack of understanding was an important catalyst to kick starting my PhD journey.

Our initial formal effort to deal with this situation where books tell a different story from the reality on ground was to embark on a year long process of writing Uganda's first Breast Cancer treatment guidelines. 'Our' refers to a group we called the Breast Cancer Working Group made up of multi disciplinary team of doctors and nurses. Whereas, this ended successfully and we even got a publication in African Health Sciences Journal, I was not contented. I was not because our guidelines had little evidence from our

own research we had not done much breast research anyway. We had largely put in our opinions granted they were based on observations we had made during our many years of practice, but on the strength of scientific evidence scale, opinions fetch the lowest score. The parts in the treatment guidelines that were not opinions were data and recommendations from research work done elsewhere outside Uganda. Why was it a big deal to have Ugandan generated data? We now know that countries need country specific data for effective cancer control strategies as suggested by the World Health Organization.

Fast forward, I now have had the privilege to be involved with 22 publications dedicated to breast cancer in Uganda, 5 of which arose from my just concluded PhD thesis, 15 were done parallel to the PhD program and 2 before it. Some of these were with the surgical residents I have had the distinct honor to mentor and supervise. Although these 22 papers are like a drop in the ocean but oceans are made of drops as someone famously said. I therefore trust that this evidence gathering exercise will surely inform part of the next set of breast cancer treatment guidelines for Uganda. They should also serve as preliminary data for more research to come. More research because there are plenty of knowledge gaps we still need to fill. The part that follows is a jargon free version of my PhD thesis abstract. Have a look.....

Breast Cancer is the commonest cancer among women worldwide. In Uganda it is the second commonest cancer among women. Breast Cancer is not one disease. It manifests in several forms which vary from low to highly aggressive behavior. Achieving a reduction in deaths from cancer is a worldwide health care priority. This research therefore explored the forms of breast cancer among women in Uganda, the vulnerability (risk) factors and how these women survive after the cancer diagnosis is made and why. The results are presented in 5 parts;

**Part I:** We categorized breast

cancer in four common forms; we found two with low aggression and two with high aggressive behavior. Aggression means rate of growth, ability to spread, response to available treatment and how long one survives after diagnosis.

We found that close to 60% of women had the two more aggressive forms of breast cancer. Before this study we believed that 20% or less develop the overly aggressive forms. The more aggressive forms do not respond to the commonly used anti cancer drugs we routinely give to every woman diagnosed with breast cancer for 2-5 years.

**Part 2 & 3:** We investigated the possible factors that increase or decrease vulnerability to developing breast cancer. We found that breast feeding was protective against developing breast cancer. The extent of this protection was more than what other studies elsewhere in the world suggest. There was no added risk if one came from the rural or urban setting. Urban setting is a proxy to a more westernized lifestyle, which lifestyle is believed to increase the risk of developing cancer.

**Part 4:** Cancer is generally regarded as early if it is stage I or II and late if it is stage III or IV. Stage relates to the degree of spread. In stage I and II there is limited spread while III and IV there is extensive spread. The degree of spread is believed to be proportional to the time between the tumour starting to when it is diagnosed. The longer the wait, the more likely that spread will occur. The more spread, the more troublesome treatment will be and higher chances of early death. What we found was that women with breast cancer waited for 29 months before reporting observed symptoms to a health worker at Mulago hospital. We considered Mulago because it is the only mostly free public facility with a whole array of the required cancer care options. The delay period didn't differ from those who had stage I or II diagnosis and those who had stage III or IV, which implied that there must

be other factors at play than just the passage of time.

**Lastly in part 5,** we looked at how long women with breast cancer survived after diagnosis. Just about 50% were alive 5 years after diagnosis. This figure is not close to the 90% or more observed among white women in Canada and most European developed countries. Also significant was the fact that 1 in 3 women didn't return for further care after the initial contact with a health worker at the Mulago Breast Clinic or the Uganda Cancer Institute. This failure to return and complete treatment contributed to early deaths.

**Recommendations** from this PhD research work are:

- Every woman with breast cancer should have the form they have determined before prescribing cancer medicines. Therefore indiscriminate use of hormonal therapy should be discouraged
- Breast feeding should be encouraged for all nursing mothers.
- Causes of excessive delay in seeking care should be investigated; decentralizing cancer care in the country is worth being accorded more consideration.
- Women should be supported to complete their treatment, perhaps by recruiting fulltime navigators to assist them.
- We need to research more to find out why Ugandan women suffer the aggressive forms of breast cancer and subsequently what can be done about it.

This work would not have been possible without standing on the high and lofty shoulders of the giant called THRiVE. I will be forever grateful to everyone who made THRiVE happen especially Professor Nelson Sewankambo. My next goal is set, I have committed that for the next 10 years, I will champion the cause to reduce breast cancer deaths in Uganda, through achieving an 80% early stage presentation. So help me God and those in this fight. 'Gakyali Mabaga'!

## THRIVE PhD alumni wins a grant for Advanced Research Training program

By Humphrey Mazigo

Shortly after receiving a certificate (receiving my PhD degree) to prepare myself to become an established researcher in my field of interest, in early February 2016, I received breaking news that I was among the few applicants whose proposals were accepted in the Advanced Research Training program under MEPI project which will start in August 2016. The main objective of the grant is to strengthen research capacity for junior faculty in Tanzania working in medical schools. The total grant cost is US\$ 30,000 and I will use it as a start-up fund to collect initial epidemiological data for my post-doctoral topic. I will recruit a Masters research student as part of the mentoring program of young researchers. The sky is indeed the limit as I thrive.

## Looking back over the Years: My Ph.D Experience

By Stella Kepha

I consider having a PhD as a licence to do research, it's the one certificate that gives people confidence that one is able to conduct research in an independent manner. In 2011, through THRIVE, I set out to obtain my research licence. In addition to gaining respect to from my peers, the PhD process gives one room to be able to spearhead an original idea and get training on the various aspects of research that are key in a successful research career such as organizing, planning, negotiation and managing people. It is also one of the fastest route to build one's publication profile. In high school I was fascinated by cell biology and it's the line I wanted to pursue, then my teacher said that nobody really knows the function of golgi apparatus. This changed during my under graduate studies, I become fascinated by parasitic diseases most of which are neglected and are common in sub Saharan Africa. Subsequently my interest shifted from basic science to operational research that bent on informing policy. I had an opportunity to conduct a clinical trial among school children addressing a public health question that remains unanswered round the school deworming programmes. Currently the World Health Organization (WHO) is implementing a road map 2020, aimed among other goals; to control soil transmitted helminth (STH) infection in endemic countries by 2020. However soil transmitted helminths are known to drive the human immune system to ensure their survival. This selfish manipulation of the immune system by STH affects the ability of an individual to fight other infection such as malaria which share same geographic distribution as STH.

I had a first class PhD training experience, under the guidance of experienced epidemiologists Professors; Simon Brooker (LSHTM) and Fred Nuwaha (Makerere University). I conducted a clinical trial which was a learning experience I had not been part of an epidemiological study before. I have gained skills in setting up and giving oversight to a field trial, field logistics management and liaison with the local community, finally analysing and making sense of data collected. One of the key skills I developed during my training is how to prepare and give talks to both scientific audiences (through conferences) and lay audiences (through community meetings). This was very helpful when preparing for my defence, hallmark of the PhD training process, the one thing I looked forward to and dreaded in equal measure. My thesis is based on four manuscripts that took me eleven months to write, six months of which I spent in Uganda (housed by the THRiVE secretariat). In addition to writing I had a chance to mingle with other PhD student with whom we shared our experiences. Makerere PhD defences are Public and process appears daunting however it's a grand opportunity to disseminate one's findings somewhat like an inaugural speech by a professor. I made a point to attend as many PhD defences as I could during my stay at Makerere just to get a feel of what to expect. I soon learned the questions asked by the examiners have a similar theme, this shaped my thesis development to seal possible loopholes.

As finalised my thesis I had a well thought out plan of how I would prepare for defence, the many pre-defences I would have. However when I finally had a defence date scheduled I was caught-up in a large cluster randomised trial preparing

for its midline survey in add, I barely had time to execute my grand defence plan. The time invested in writing the thesis was very helpful as I understood my work in and out. Having attended various defences I had an idea of what to expect, with the help of my fellow THRiVE colleagues I had a mock defence that gave me courage to talk about my work. A day before my presentation I could not speak coherently, I had an adrenaline surge with reality sinking in that I just had a single hurdle I need to jump to be done with the PhD process. However feedback I got from the audience was that I had a convincing defence. A PhD defence is the hallmark of the entire PhD process, I now in retrospect appreciate that it important to look at the process in entirety, everything in the PhD process contributes to a successful finish. It is important to adequately prepare for the defence, by ensuring the data collection process is rigorous, data analysis is robust and the finally that the findings are well articulated.

Now that I have my licence my next step is to work towards being able to attract funds. For a start I am keen to be mentored by senior scientists as I find my place in the research world. I am fortunate to work under the guidance of Dr. Rachel Pullan an epidemiologist based at LSHTM, interested in targeting control of neglected tropical diseases. She is the Principal investigator of a cluster randomised trial called TUMIKIA on the Kenyan coast that is evaluating different treatment strategies on the transmission of soil transmitted helminths. Within this trial am looking at a question that I can pursue start applying for funds. My aim is to see how I can within this trial setting start my journey in attracting funds.

# Training Health researchers into vocational excellence in East Africa (THRIVE) Grant Number: 087540

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