

Patient-centered education and care

A PILOT STUDY IN UGANDA



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PREFACE

BY DR. ROBERT KALYESUBULA

Non-Communicable diseases(NCDs) are the leading cause of death across the world. The majority of morbidity and mortality related to NCDs occur in Low and Middle-Income countries like Uganda where the capacity to handle such chronic diseases is quite limited.

Therefore, it was with great pleasure that we received the news of a three-year grant to support the development of a center of excellence for NCD care in Uganda from the Else Kröner Fresenius Stiftung.

This report summarizes the past year's achievements of the ACCESS Uganda partnership with colleagues from Yale University, Johns Hopkins University, Friedrich-Alexander University Erlangen Nürnberg, Charité Universitätsmedizin Berlin and Makerere University.

The effort represents a multi-national, interdisciplinary collaboration which has the potential to revolutionize NCD prevention and management in low- and middle-income settings.

We thank the Else Kröner Fresenius Stiftung for supporting this vision and contribute to efforts that have enabled us to reach out to over 18,000 community members in Nakaseke.

Please enjoy reading the report.

Dr. Robert Kalyesubula
is the President of ACCESS, Uganda

Probability of dying from a non-communicable disease*

THE PROBLEM

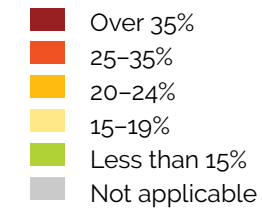
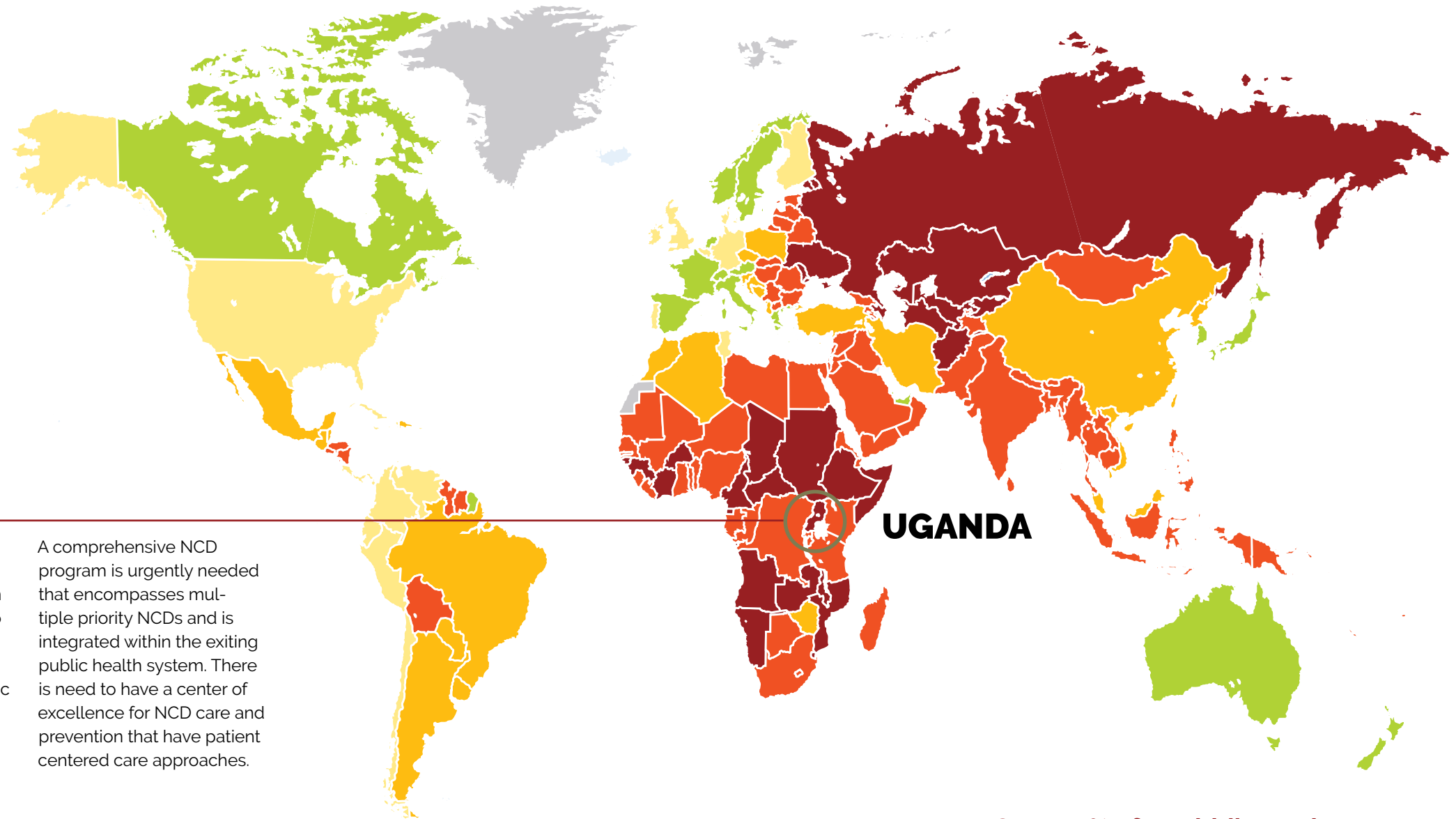
Uganda is one of the countries in Sub-Saharan Africa where the burden of non-communicable diseases (NCDs) has overwhelmed already under-resourced health systems.

The rising burden from NCDs poses new challenges to the health system requiring innovative ways to prevent and manage these diseases NCDs such as hypertension, diabetes, chronic obstructive pulmonary disease and chronic kidney disease have not been prioritized by the Ugandan health care system and the increase in disease burden has out-paced health service institutional and human capacity to act effectively and efficiently.

A comprehensive NCD program is urgently needed that encompasses multiple priority NCDs and is integrated within the exiting public health system. There is need to have a center of excellence for NCD care and prevention that have patient centered care approaches.

Over 90% of morbidity and mortality related to non-communicable diseases occur in low- and middle-income countries (LMIC).

* Between the ages of 30 and 70, 2008, % (Source: WHO)





INTRODUCING **ACCESS**

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ACCESS is known to the community as a pioneer provider of comprehensive health services and community empowerment to the people of Nakaseke district and beyond.

ACCESS operates through three strategic pillars and subthemes that together form the institutional structure and define the delivery mechanism.

ACCESS focuses on health care delivery and research through a network of community health workers, static clinics as well as strategic collaborations with existing health facilities and international collaborators.

We provide health care to over 5,000 patients annually. We offer training to both lay and professional health workers through the ACCESS Health training Institute(AHTI) and education to orphans and other vulnerable children.

We support 444 orphans and other vulnerable children through the provision of education support in form of tuition fees as well as material support. 163 Health professionals are attending the ACCESS Nursing school while 46 community health-workers have been trained and commissioned to support the community.

The third strategic pillar is about economic empowerment where the target beneficiaries are the elderly and adolescent youth who are provided with small start-up grants to generate income for sustainable improvements in their lives



THE **NCD PROJECT**

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A collaborative effort between the Friedrich-Alexander University Erlangen-Nurnberg, Germany, the African Community Centre for Social Sustainability (ACCESS) Uganda and Yale University School of Medicine, USA, yielded a 3-year (2016-2019) grant fund to facilitate the establishment of a Centre of Excellence for Non-Communicable Diseases (NCDs) in rural Uganda. NCDs such as hypertension, diabetes, chronic obstructive pulmonary disease and chronic kidney disease will be at the center of the program that is expected to identify and support NCD

disease patients and provide cutting edge findings that will be used to inform national policy on sustainable management of these diseases at community level. The aim is to empower patients to become managers of their diseases. In addition, the project will provide global health education opportunities for medical students and physicians in training from Uganda, USA and Germany.



Nursing students supported by EKFS at the AHTI

BUILDING CAPACITIES

Funding provided by **Else Kröner-Fresenius Stiftung** has been primarily aimed at capacity building to a) improve ACCESS' outreach to the community and b) improve NCD related education among Ugandan trainees. Funding has allowed ACCESS to increased capacity to handle NCD through the hiring of a Medical and Clinical officer to be stationed at the Life Care center full time.

The team will receive and treat recruited patients into the program over the next project period. Focused training and medical supplies will be provided to continue improving the facility intervention.



Prof Felix Knauf and Dr. Siddharthan with one of the Nurses awarded a scholarship

Nursing scholarships

The AHTI will have students trained in NCD management and commissioned to give support to the communities upon graduation.

A nursing scholarship fund was developed and it commenced with the award of 7 scholarships on a competitive basis this year. An additional 7 will be selected for the new semester to make a total of 14. This will boost human capacity to handle NCDs in the district and other parts of the country.

Ugandan students' rotation at Yale

Two medical students from Makerere University College of Health Sciences were additionally awarded scholarships to undertake short term training from Yale University.

CENSUS



CENSUS

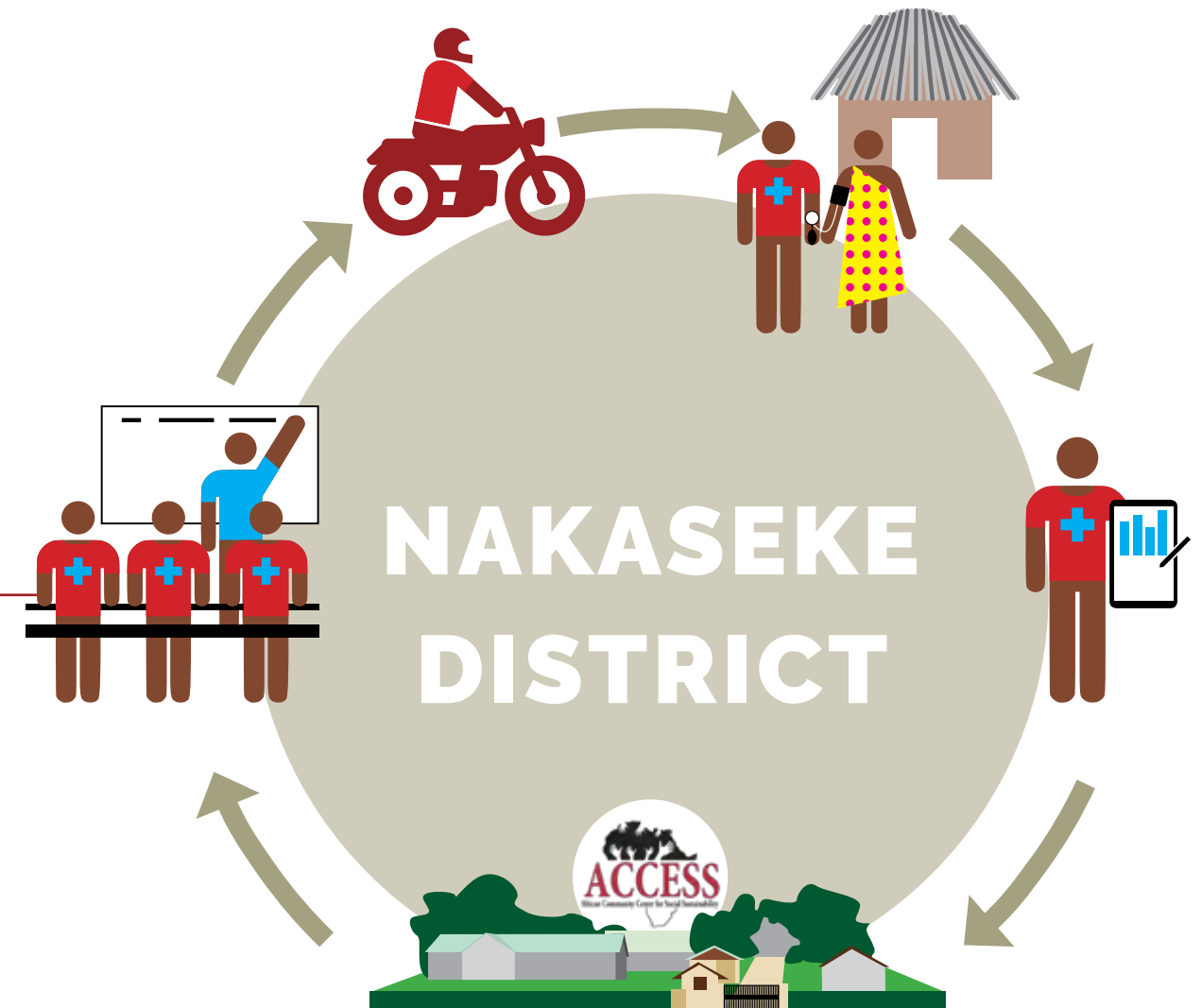
As part of establishing the community burden of NCDs and increasing awareness of NCD care at ACCESS, we have carried out a census to establish the current status of NCDs from three sub-counties of Nakaseke. The census is the first population-based NCD survey's in Nakaseke and one of the first in the region.

Qualitative interviews with patients and providers additionally identified enablers and barriers to NCD care which will inform scalability of our approach. A team of 18 Research Assistants (RAs) was recruited, trained and equipped to effectively achieve this task.

So far, 8,869 households with 16,486 participants have been reached through the census. A total of 859 participants reported having an NCD, with 582- hypertension, 104 diabetes mellitus, 84- asthma, 54-COPD and 35 having chronic kidney disease.



Research assistants preparing to go to the field.



Teaching



Community Health Worker (CHW)
Village Health Trainer (VHT)



Village People



Physical examination



Research Assistant (RA)



POCKETDOKTOR BOOKLETS

POCKETDOKTOR BOOKLETS

The Pocketdoktor is a pocket-sized innovative educational tool to facilitate dialogue around the subject of NCDs. The booklet moved from concept to print during the year with two books already translated to Luganda; the widely spoken local language.

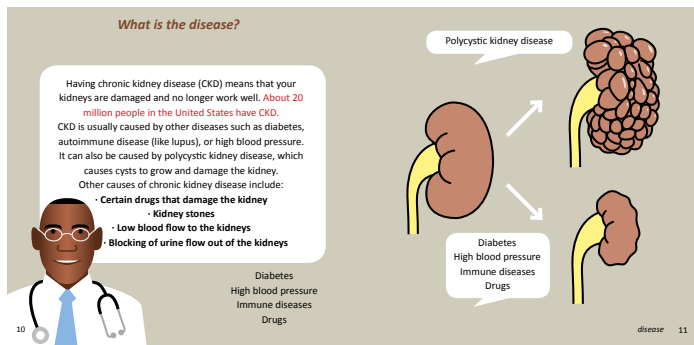
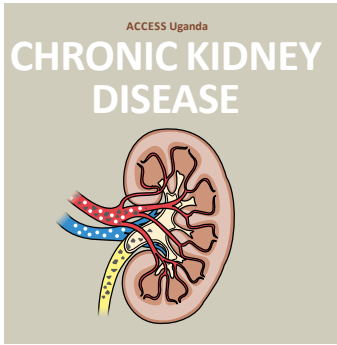
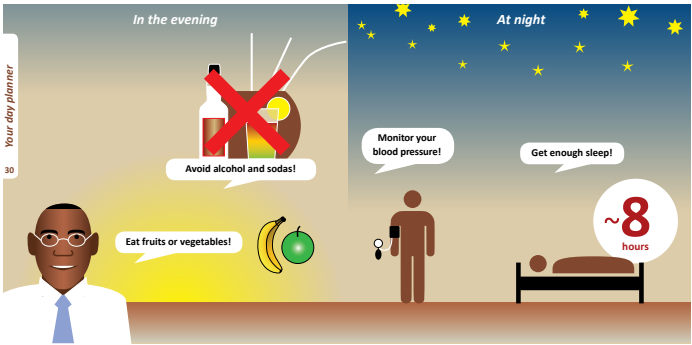
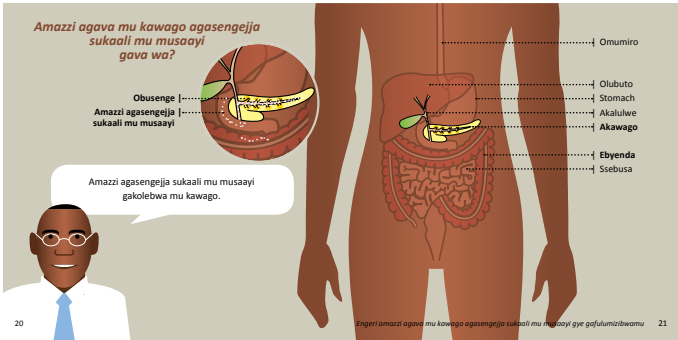
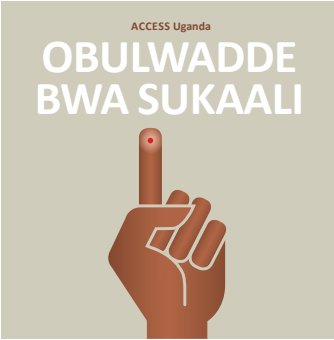
The style, colour and general presentation is simple, straight forward and clear.

These books will be key tools to provide and study the effects of patient centered care. The books are 34 pages long and describe diagnosis, pathophysiology, treatment and long term management of NCDs.

Dr. Richard Munana explores the Pocket Doktor booklet with community members.



The two completed booklets are for hypertension and diabetes while the one for chronic kidney disease awaits translation. The COPD one will be done in the next project period.



GLOBAL HEALTH EDUCATION

The ACCESS site as well as other hospitals in Germany and USA will offer clinical training facilities for medical students and residents from Uganda, Germany and the USA. To date, two students from Germany have visited ACCESS and Nakaseke Hospital for such training experiences and exposure.

The students are given an opportunity to experience medical care from resource limited settings by visiting Nakaseke Hospital, taking patient histories and having discussions with the local doctors.

Students are also able to participate in the research projects available at ACCESS and undertake mentored lectures mainly focused on common tropical diseases. The learning environment is highly conducive and the students reported a great global health experience during their stay with us.



Vicky and Sonja from Erlangen University take care of patient with Mr Sewanyana at the ACCESS Clinic.



WHAT'S NEXT?

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The project has been running for one year now and has ended with the census as a key project deliverable. Plans for the next year emanate from the census-created baseline that will see the recruitment of a cohort of NCD patients for a more focused treatment and follow up program. To do this, both the ACCESS facility staff and the recruited 25 VHTs will receive prior training in NCD case management.

Appropriate medicines and drugs will be stocked at the Life Care Centre to facilitate treatment and more data collection on the use and application of the PocketDoktor booklet.

The CHW curriculum will be revised through a consultative process with the national leaders at the center and district levels so that the changes are accepted nationwide. Thereafter service providers will be re-trained about the change in the NCD curriculum.

The PocketDoktor booklets have been pre-tested. During the second year of implementation, they will be rolled out to the communities. It is envisaged that the COPD booklet together with the kidney booklet will be out and in use. NCD surveillance will continue and patient groups will be initiated to increase community coping mechanisms.

The program will continue administering the nurses scholarship program and stipends in the next year of implementation and also continue with the global health education.

We plan to work with the district health administration and the Ministry of Health to improve NCD care within the Nakaseke area.

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Dr. Robert Kalyesubula

is a nephrologist in Uganda and deputy director of the post graduate training program at Makerere University.



Dr. Felix Knauf

is an internist and nephrologist at the University Erlangen, Germany.



Dr. Philipp Kirchhoff

is a general surgeon who completed his medical training in Switzerland.



Dr. Trishul Siddharthan

is a third-year medical resident in Yale's Internal Medicine Primary Care Program. He spent 6 weeks in Uganda as a Johnson and Johnson Global Health Scholar in the fall of 2012.



Dr. Asghar Rastegar

Professor of Medicine, is a native of Iran and he received his B.A. (chemistry) and M.D. from the University of Wisconsin (Madison).



Dr. Tracy Rabin

is an Internist and Pediatrician who also has a MS degree in Immunology and Infectious Diseases from the Harvard School of Public Health.



Dr. Steven Coca

is an Internist and Nephrologist who joined the Yale faculty in 2009 as an Assistant Professor in the Department of Internal Medicine.



Dr. Irene Nakalema

is a medical doctor who received her MBChB at Makerere University College of Health Sciences.

THE TEAM

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He trained in Internal Medicine at Makerere University and conducted postgraduate training at McMaster and Yale University. He is also the founder of the African Community Center for Social Sustainability (ACCESS) which provides care and support for vulnerable groups through medical care, education and income-generating projects.

He went to medical school in Freiburg, Paris and Berlin. He completed his residency in internal medicine and renal fellowship at Yale University. He joined the Yale faculty in 2011. Felix Knauf spent 2 months in Uganda in 2007 with the Yale Global Health Program. Together with Philipp Kirchhoff, he is the co-founder of PocketDoktor.

He has also conducted research at Yale University investigating epithelial transport mechanisms in the stomach. Since 2010 he worked as a consultant surgeon at the University in Basel. Currently he is Senior Colorectal fellow at the University Hospital in Cambridge, UK. He founded PocketDoktor with Felix Knauf in 2012.

Areas of research include interprofessional training, shared decision making and medical education as well as international health.

He did his postgraduate training in Internal Medicine and Nephrology at the Hospital of the University of Pennsylvania in Philadelphia where he also served as Chief Medical Resident and Clinical Instructor. In his role as the Director of the Office of Global Health Program in the Department of Medicine at Yale University, he oversees an extensive program in 6 major sites devoted to capacity building in resource-poor countries.

She joined the Yale faculty in 2011 as an Instructor in the Department of Internal Medicine and Assistant Director of the Office of Global Health; she also serves as the Co-Director (Yale) of the Makerere University-Yale University Collaboration, a medical capacity building partnership.

He also obtained an MS degree in Epidemiology and Public Health from the Yale Graduate School of Arts and Sciences in 2009. He is an investigator in the Yale Program of Applied Translational Research, and has active funding and projects related to acute and chronic kidney disease.

She is currently completing a masters in internal medicine at Makerere with an focus on Cardiology.

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